DOCUMENT RESUME

ED 270 931 EC 182 931

AUTHOR	Taylor, Steven J.; And Others
TITLE	The Nonrestrictive Environment: A Resource Manual on Community Integration for People with the Most Severe Disabilities. Field Test Version.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	Office of Special Education and Rehabilitative Services (ED), Washington, DC.
PUB DATE	Jan 86
CONTRACT	300-85-0076
NOTE	152p.; A part of the Community Integration Project. For related documents, see EC 182 932-933.
AVAILABLE FROM	Center on Human Policy, 123 College Place, Syracuse University, Syracuse, NY 13244-4130 ($5.50).
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC07 Plus Postage.
DESCRIPTORS	Adoption; Community Programs; Community Resources; Community Services; *Family Role; Foster Care; *Group Homes; *Multiple Disabilities; *Normalization (Handicapped); Services; *Severe Disabilities; Vocational Education

ABSTRACT

The report examines the status of community integration for people with the most severe disabilities. Information is drawn from literature reviews, telephone surveys of over 50 programs nationwide, and visits to 5 community service systems in 4 states. An initial section outlines basic principles for community integration, followed by a review and critique of the continuum concept, the notion that persons with a range of disabilities need to live in a range of most restrictive to least restrictive settings. Analysis of the nonrestrictive concept stresses the importance of supporting children in natural, foster, and adoptive families. Ways in which good families for children can be found are considered and illustrated by examples. Types of support that must be offered such families are noted - including staff and professional support and case management. Participation in community life is stressed as is the need for integrated and individualized vocational services. Commitment flexibility and accountability are emphasized. Guidelines for operating group homes are presented, including avoiding institutional trappings and teaching functional life skills. (CL)

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THE NONRESTRICTIVE ENVIRONMENT:
A RESOURCE MANUAL ON COMMUNITY INTEGRATION FOR PEOPLE WITH THE MOST SEVERE DISABILITIES

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January, 1986

Field Test Version

EC 182931

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THE COMMUNITY INTEGRATION PROJECT

is designed to provide technical assistance and disseminate information on model programs and practices for serving persons with the most severe disabilities in integrated community settings.

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This manual was prepared with support from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Handicapped Research, awarded to The Center on Human Policy, Division of Special Education and Rehabilitation, Syracuse University (Contract No. 300-85-0076). The opinions expressed herein do not necessarily reflect the position or the policy of the U.S. Department of Education and no official endorsement by the Department of Education should be inferred.

ACKNOWLEDGEMENTS

Many people contributed to this manual directly or indirectly. The staff of the Community Integration Project, including Douglas Biklen, Alison Ford, Luanna Meyer, Jan Nisbet, Jo Scro, and Stan Searl, contributed many of the ideas found in the manual. Members of the project's National Advisory Committee also offered numerous suggestions and ideas. Special thanks to Bob Perske, Gunnar Dybwad, Charlie Lakin, Bill McCord, Lou Brown, John O'Brien, Jeff Strully, Jerry Provencal, Harvey Zuckerberg, Lyn Rucker, and others. Thanks also to Mike Morris, Dianne Ferguson, Kathy Schwaninger, Wade Hitzing, Nancy Rosenau, Mark Maxwell, Sheryl Dicker, Mike Callahan and Gloria Kishi for their ideas. We also want to thank the many people involved with innovative programs who took the time to talk with us, open their homes, and provide us with information about what they are doing. Finally, thanks to the subcontractors on the Community Integration Project, the United Cerebral Palsy Governmental Activities Office and The Association for Persons with Severe Handicaps, and Naomi Karp of NIHR for their ongoing support.

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PREFACE

For the past year, we have been looking into the "state of the art" in community integration for people with the most severe disabilities - people with multiple disabilities, severe and profound mental retardation, challenging behaviors, and medical involvements. We have reviewed manuals, books, and articles on community living, vocational services, family supports, and other services. We have conducted an indepth phone survey with over 50 innovative programs across the country. We have visited five community service systems in four states and we have talked to dozens of people. In this manual, we tell you about what we have learned.

The state of the art in community integration is moving rapidly. Blink, and you might miss it. If you're not careful, you might get the impression that the major issues dominating the field have to do with whether people with severe disabilities are better off in institutions or in less restrictive community environments or in large or small facilities. Yet, these are yesterday's issues. To be sure, these issues are still real. With over 100,000 people with developmental disabilities living in public institutions and thousands of others living in other kinds of institutions, it would be foolish to suggest that they have gone away. But the state of the art has moved beyond these issues. That people with the most severe disabilities can live in the community is not just an idea. It is a reality at a growing number of places across the country. The issues today have to do with how these people should be served in the community and what arrangements foster the greatest degree of integration.

For the past decade and a half, the concept of "least restrictive environment" has been a guiding principle for services for people with disabilities. As the state of the art evolves, however, this principle is gradually giving way to a new one: what might be termed the principle of nonrestrictive environment. The nonrestrictive environment doesn't restrict or regiment. The nonrestrictive environment is not a home-like facility. It is a home; supports and services may need to be built in, but it's a home nonetheless. Everybody needs a home. This is the state of the art in community integration.

This manual starts off with an introduction that outlines some basic principles for community integration. We next move to a discussion and critique of the "continuum concept," the notion that people with disabilities need to live in facilities ranging from the most restrictive to the least restrictive. The following section looks at how some service systems and agencies have developed homes for children and adults with severe disabilities and describes some of the services people may need to live successfully in the community. After this, we turn to a discussion of integrated vocational services. In the next section, we consider what makes community integration seem to work. It's not just a matter of technical know-how, but commitment, flexibility, and accountability. The remainder of the manual covers some of the emerging controversies in community integration. In order to make this publication useful as a resource manual, we have included several appendices. Appendix I lists some practical ideas, strategies, and resources for developing integrated community services. Appendix II lists agencies which we looked to as "models" for innovative ideas on how to integrate people with severe disabilities into the community.

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1985

INTRODUCTION

Throughout the 1970's and early '80's, the issue of deinstitutionalization dominated the attention of the field of developmental disabilities. Spurred by law suits, exposes, federal initiatives, and parent, consumer, and professional activism, the populations of public institutions have declined at a steady pace. State representatives, agency administrators, parents and consumers, and professionals have devoted considerable discussion to the issue of institutions versus community living. Are institutions more cost-effective than community programs? Do people learn more in institutional or community settings? Are smaller facilities better than larger ones? The issue of deinstitutionalization will continue to command attention for the forseeable future.

It is time, however, to devote equal attention to the quality of life in the community. The challenge today is not simply to open the doors of the institution. The challenge is to create a network of humane, effective, and integrated services in the community for all people with developmental disabilities.

Is Community Integration A Good Idea?

Based on a study of "mainstreaming" programs for students with disabilities, one of our colleagues, Bob Bogdan (1983), wrote an article entitled, "'Is mainstreaming a good idea?' is a silly question." He said that asking whether mainstreaming is a good idea is a bit like asking whether Tuesdays are a good idea. We've all had good Tuesdays and bad Tuesdays. Yet no one would seriously consider doing away with Tuesdays simply because we've had some bad ones. So it is with mainstreaming. We can find good examples and bad examples. The question is how to make mainstreaming work.

Is community integration a good idea? We can find excellent examples of community integration. As some researchers, policy-makers, and professionals debate the institution versus community issue, others have been working to develop integrated community living arrangements and job sites for people with the most severe disabilities. There are an increasing number of places across the country where people with the most challenging needs--people with severe and profound mental retardation, autism, challenging behaviors, multiple disabilities, and medical involvements--are living in the community.

We can also find some bad examples of community integration. Indeed, some practices associated with deinstitutionalization do not represent community integration at all. In one Northeastern state, newly constructed units on the grounds of institutions are referred to as "community residences." In many other states, deinstitutionalization has meant "transinstitutionalization"; that is, people have moved from large public institutions to smaller, but equally restrictive private ones, including nursing homes. Even in some relatively small facilities, life is just as segregated as in larger institutions. For some families, "community integration" means keeping their children at home without the necessary services and supports they need.

How can we make community integration work? Before we can answer this question, we must look at what community integration means.

Principles for Community Integration

What does community integration mean? Is it the same as "least restrictive environment" or "normalization"? Does it simply mean that all people with developmental disabilities should live in group homes and attend community-based day programs? How can we even begin to answer these questions?

By looking at "model" programs nationally, we can find some answers to these and other questions. What makes some states, regional service systems, and agencies stand out is that they are committed to a clear set of principles. To be sure, no program stacks up perfectly against its principles. No state, no region, no agency has developed ideal or perfect services. Yet some are moving in an exciting direction. For these programs, principles are not merely words that sound good on paper. Rather, they provide guidelines for day-to-day decision making and a way to gauge progress toward a vision of what services should look like. They tell us what community integration means in practice.

1. All people with developmental disabilities belong in the community. People running the best, most innovative community programs do not simply believe in the "least restrictive environment." They believe that all people, regardless of the severity of disability, belong in the community. As Lyn Rucker, the Executive Director of Region V Community Mental Retardation Services in Nebraska, has written, "Put simply, if decision makers believe that everyone will be served and integrated in the community, half the struggle is over. In systems where that attitude is not embraced, I have seen every conceivable

artificial barrier thrown up as a block to providing appropriate, integrated services for everyone." As a corollary to this principle, people with the most severe disabilities should not have to wait until everyone else is placed out of institutions before they have the chance to live in the community. To the contrary, they should be among the first.

2. People with severe disabilities should be integrated into typical neighborhoods, work environments, and community settings. Where do typical people live, work, play, go to school, and shop? This is where people with developmental disabilities, including those with severe disabilities, should do these things. What's a typical neighborhood, work environment, or community setting? In the field of special education, Lou Brown (Brown, et al., 1977) and others came up with the "principle of natural proportions" to serve as a guideline for determining where people with severe disabilities should live, work, and recreate.

3. Support the placement of people with severe disabilities in homes and natural community settings. One of the great ironies--and tragedies--of traditional service systems is that they have undermined families. It has often been easier for parents to have their children institutionalized or placed in other out-of-home settings than to receive in-home support. Parents may not be perfect, but we'll never invent anything better. As Ed Skarnulis has stated, "Support, don't supplant, the family." In other words, put your resources into supporting people in natural settings. This is a critical principle and one

to which we will return later.

4. Community living arrangements should be family-scale. As Rothman and Rothman (1984) point out, the field of developmental disabilities has been obsessed with trying to determine the optimal size of a community residence. Is eight better than ten or ten better than twelve? Of course, the larger the setting, the less personal and more regimented the care. Certainly, people with severe disabilities don't seem to do well in large settings. However, it is foolish to think that small size alone, in isolation from other factors, will guarantee a high quality of life or high degree of integration. The debate about size detracts attention from this. We think community settings should be "family-scale." How large is this? Two or three people living together meet the definition of family-scale. Perhaps more in some cases. Seven or eight people together seems like too many; this invites an institutional atmosphere. Any absolute limitation on size will be arbitrary (which is not to say that a limitation should not be set). The "state of the art" for people with severe disabilities today includes settings ranging in size from one to six, although places like Region V in Nebraska are moving to settings no larger than three or four people.

5. Encourage the development of social relationships between people with severe disabilities and other people. "Community" is not only a place to be. It is a feeling of belonging among human beings. People with severe disabilities need friends and other people who care about them--just like

other people. If there has been one thing lacking in our service systems, it is the lack of opportunities people have to develop close, mutual, and ongoing relationships with other people. No amount of professional services can replace the need people have for friendship. In fact, many "state of the art" approaches for serving people with the most challenging needs stress the importance of bonds between people with disabilities and service providers. John McGee's (McGee, Menolascino, & Menousek; in press) "Gentle Teaching" illustrates this. Some settings and arrangements inhibit relationships; others foster them.

6. Foster participation in community life and the development of community living skills. This principle implies two things. The first has to do with social integration. Community integration doesn't just mean physical placement in the community. Some people living in the community are just as isolated and segregated as they were when they were living in institutions. They live in a facility with eight or ten or twelve other people; get up in the morning and board the van; go to a sheltered day program; return to the facility in mid-afternoon; and, if they're lucky, go on a field trip as a group in the evening or on week-ends. Community integration also means interacting with other people in the community.

The second implication relates to the opportunity to learn practical life skills. Community residences have been defined largely as places to live, rather than learn. To be sure, community settings should not be treatment centers. Neither should they be custodial facilities. In special education, instructional approaches have been developed to teach students with the most severe disabilities "functional" life skills ("functional" means that if you cannot do something for yourself, someone will have to do it for you). In Madison, Wisconsin, DeKalb, Illinois, and dozens of other places across the country, students with severe disabilities are learning to take a bus, order in restaurants, select and pay for groceries, cook, clean houses, and perform hundreds of other tasks once deemed impossible for them to learn. (Taylor, 1982) These instructional approaches have not been adapted by people who work in community living arrangements. Many of them could be. After all, in any community living arrangement, somebody has to go grocery shopping, cook meals, wash dishes, and clean the house. People with severe disabilities should be involved in these activities.

7. Involve parents and consumers in the design, operation, and monitoring of services. Parents and consumers should be treated not merely as passive clients, but as partners in developing services. Professionals may come and go; the parents and consumers will always be there. It's popular to be "down" on parents in some circles these days. "The parents don't know what's best for their children" is a common sentiment. Thus, some professionals blame parents for resisting community placement. Yet parents did not create the institutions; professionals did. If parents do not trust the community, then the burden is on professionals to show that they can develop high quality services in the community. The experience has been that good models in the community create a demand among all parents for

more community services.

Consumer involvement is an idea whose time has come. Just as parents and people with physical disabilities organized to demand quality services in the 1960's and 70's, people with developmental disabilities are beginning to demand their human and civil rights. Self-advocacy is here to stay.

Parent and consumer involvement is not merely a nice thing to encourage. In looking at model programs, we have found that parents and consumers play a major role in supporting innovative efforts and safeguarding the quality of services.

CAUGHT IN THE CONTINUUM

The concept of a continuum of educational, vocational, or residential services is a popular way of thinking about services for people with disabilities. Just about everyone believes in the "full continuum of services" and most service systems are designed this way.

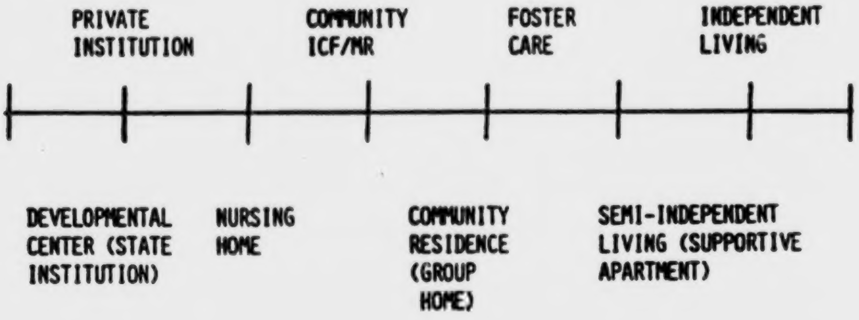
The continuum concept was developed in the 1960's to refer to a range of special education placements from the hospital to the regular class (Reynolds, 1962). Years later, the federal regulations for P.L. 94-142 incorporated this concept and required a "continuum of educational placements."

The continuum can be conceptualized in terms of a straight line running from "most restrictive" to "least restrictive placement." At the most restrictive end of the continuum stand segregated facilities (institutions, special schools, special day program facilities). At the opposite, "least restrictive" end of the continuum are normal settings (independent living, regular classes, competitive work). The assumption is that people with the most severe disabilities will be served at the most restrictive end of the continuum and those with the mildest disabilities will be at the least restrictive end. As people acquire additional skills, they are expected to move from the most to the least restrictive placements.

In the field of residential services, the continuum concept quickly caught hold in the 1970's. It represented an appealing alternative to the "no option" choice of community living with no supports or institutionalization. And who could argue with the principle of "least restrictive environment"? Before long, most states had incorporated the continuum concept in their design of residential services.

The residential continuum looks something like this: institution--on-grounds "community facility"--nursing home--community intermediate care facility for the mentally retarded (ICF/MR)--group home (community residence or halfway house)--foster home--semi-independent living. Let's take a closer look at what the continuum means for people with the most severe disabilities.

FIGURE 1


PRIVATE INSTITUTION
COMMUNITY ICF/MR
FOSTER CARE
INDEPENDENT LIVING
DEVELOPMENTAL CENTER (STATE INSTITUTION)
NURSING HOME
COMMUNITY RESIDENCE (GROUP HOME)
SEMI-INDEPENDENT LIVING (SUPPORTIVE APARTMENT)

CONTINUUM OF RESIDENTIAL SERVICES

Institutions. This is where some people think the severely disabled should be: "There will always be a need for institutions for the severely and profoundly retarded, the medically fragile, and the behaviorally disordered." The populations of public institutions for the mentally retarded and developmentally disabled have declined at a steady pace since the late 1960's to approximately 111,000 today (Epple, Jacobson, &

Janicki, 1985). However, in many states, people with severe disabilities continue to live in institutions. The populations of public institutions include a growing percentage of people with severe and profound retardation, multiple disabilities, and behavioral involvements. While some people think that the most severely disabled need institutions, many others believe that these are the ones who are harmed most by institutionalization. It is precisely people with the most severe disabilities who most need the kind of personal and individual attention only a home can offer.

On-grounds "Community Facilities." These are newly constructed units on the grounds of public institutions. Several states are currently involved in constructing clusters of eight to twelve bed "group homes" at old institutions. New York State plans to construct 1,000 such beds over the next several years. Of course, people with severe disabilities are likely candidates to be placed in these facilities.

Nursing Homes. In the early and mid-1970's especially, many people with multiple disabilities and medical involvements were transferred from large public institutions to nursing homes. Lakin, et al. (1982) estimated that as of 1980, over 69,000 people with mental retardation were living in nursing homes. In some states, nursing homes have given "deinstitutionalization" a bad name.

Community Intermediate Care Facilities for the Mentally Retarded ICF's/MR. These are Medicaid-funded facilities. ICF/MR's range from smaller group homes to mini-institutions for hundreds of people. When people with severe disabilities are served in the community, this is where they usually end up. Some states have placed a large number of people with severe disabilities in community ICF's/MR. Michigan has developed a large number of relatively small (six-person) "AIS/MR" facilities ("Alternative Intermediate Services for the Mentally Retarded"). It is not uncommon to hear, even among advocates of community living, that "the severely disabled need to be in ICF's." To say that someone needs to live in an ICF/MR is a meaningless abstraction, which, as we will see, confuses facilities with the services people need to live in the community.

Group Homes. When most people think of community living, they think of group homes. It's as though people with mental retardation and developmental disabilities come in groups of six, or eight, or ten, or twelve. Group homes are a vast improvement over institutions and other "more restrictive" placements. However, as we will see, group homes are rapidly becoming an outmoded concept, especially for children. Few people with severe disabilities have ended up in group homes anyway.

Foster Homes. These are often called "family care" or "specialized foster care" homes. For people with developmental disabilities, foster care was one of the first alternatives to institutionalization, other than living independently or with family members. In traditional foster care, families receive a room and board payment to care for a person in their home. More recent schemes ("personal care," "community training homes") provide for a payment for foster families for training within the home. In most states, foster care has been used for adults and children with mild disabilities. However, there are some notable exceptions. In Nebraska and Michigan, in particular, foster families are caring for people with the most severe disabilities. We look at this in depth later.

Semi-independent Living. This usually refers to "transitional" apartments for people with mild disabilities. Typically, people served in these programs receive supervision and support on an "as needed" basis. People with severe disabilities have almost never been served in these programs.

Independent Living. For people with developmental disabilities, this means everything from living with the support of friends in decent houses and apartments to living in substandard conditions in urban slums. Some "street people" were in the first wave of deinstitutionalization. Independent living has not been an option proposed for people with the most severe disabilities.

The continuum concept was extremely forward-looking for its time. Before long, however, practical experience began to point out a number of problems with this notion. Beginning in the late 1970's and early 80's, people in the field like Wade Hitzing (1980) started to argue that the continuum concept was full of pitfalls.

For people with the most severe disabilities especially, the continuum concept has serious problems.

1. People with severe disabilities get stuck at the wrong (most restrictive) end of the continuum. As long as services are conceptualized in terms of a continuum, somebody will wind up at

the most restrictive end; this means people with severe disabilities.

2. The "most restrictive" placements do not prepare people for the "least restrictive" placements. One often hears that people with severe disabilities "aren't ready" to live in the community. The irony is that the most restrictive placements do not give people opportunities to learn the skills necessary to live in the least restrictive placements. That is to say, the skills needed to function in a home, grocery store, or restaurant are different from those that can be taught at a segregated setting. People with severe disabilities end up spending their whole lives "getting ready" for something that is not going to happen.

3. The "most restrictive" placements aren't necessary. Even if the continuum concept were valid, we could eliminate the placements on the restrictive end of the continuum. This isn't based simply on belief. It is based on practical experience at an increasing number of places across the country. From Michigan to Nebraska, from Rhode Island to Oregon, from Pennsylvania to Kentucky, from New York to Arizona, people with severe and profound mental retardation, multiple disabilities, medical involvements, and challenging behaviors are living in the community. For any person with a given disability living at an institution, there is another person with the same disability living successfully in the community. This is the "developmental twin" argument developed by Tom Gilhool and others (Gilhool and Stutman, 1978).

4. There are always "bottlenecks" in the continuum. The concept implies that people can move easily from one placement to the next. In point of fact, anywhere you go you can find people waiting to move to the next, less restrictive placement. They don't move because placements aren't available. In short, movement doesn't depend on people's skills; it depends on the availability of services.

5. The continuum implies that people have to leave their homes every time they develop new skills. If the continuum concept worked as it's supposed to (which it doesn't), people would have to be uprooted continuously. Life would be a series of stops between less and less restrictive residences. What would this do to someone's sense of home? What would it do to relationships with roommates, support staff, and neighbors? To be sure, there may be reasons in anyone's life why he or she should move. Learning to do some things independently isn't one of them.

6. Resources are concentrated at the most restrictive end of the continuum. One thing that the continuum concept does accurately represent is the allocation of resources devoted to different placements. Most funds and staff go to the restrictive end. As one moves through the continuum, fewer resources are available. To receive support, you have to be in a restrictive placement. The more typical and normal the living situation, the fewer resources available. In effect, we've told people they can have services or a decent life, but not both.

7. Services shouldn't be "restrictive." The continuum con-

cept confuses the issue of restrictiveness (presumably restrictiveness of civil rights) with intensity of services (needs). To be sure, some people need intensive supports and services. This does not relate to their rights. While "least restrictive environment" is a seductive concept, the right to a "nonrestrictive environment" is a better one.

8. The continuum emphasizes facilities, not services. As Gunnar Dybwad (in a personal conversation) has put it, "Every time we identify a human need in this field, we build a building." This strikes at the heart of the matter. Stripped to its essentials, the continuum concept has to do with facilities and not services. As a field, we have been very successful at constructing facilities, first large ones and now smaller ones. We haven't been nearly as successful in meeting people's needs. Why is it that people with severe disabilities have to live in facilities and the rest of us get to live in homes?

THE NONRESTRICTIVE ENVIRONMENT: IN SEARCH OF A HOME

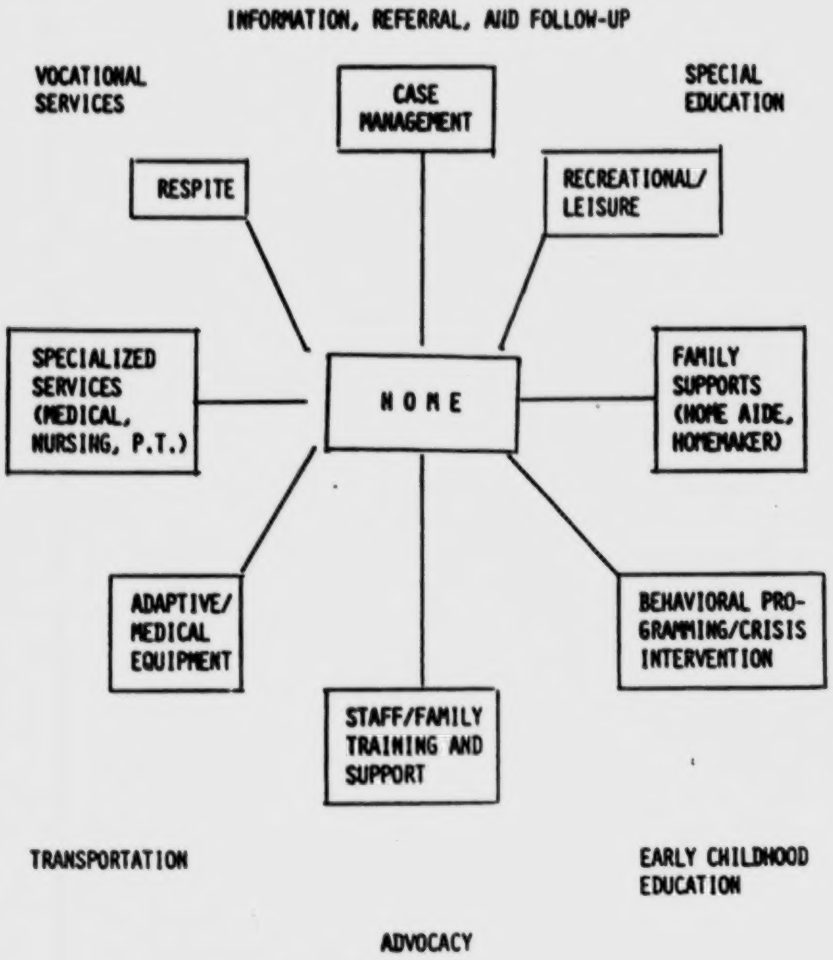
The state of the art in community integration is evolving at an incredibly rapid pace. The professional and research literature doesn't reflect this. Reading the latest books and journal articles on residential services, you get a rehash of the arguments in favor of institutions versus large group homes. When, however, you take a close look at the most experienced community service systems, you find that the debates that have dominated the field over the past decade and a half are largely irrelevant. The state of the art today is moving beyond the notion of a continuum (institution--group home--independent living) toward more individualized and integrated services. People are talking about homes, not facilities or "group homes," for all people with developmental disabilities.

Since the beginning of the national trend toward deinstitutionalization, group homes have sprung up across the country. In many places, community living is equated with living in a group home. The problem with group homes is that they are almost never homes.

This is not to suggest that group homes are always, or usually dehumanizing settings. To the contrary, many group homes are nice places, staffed by caring and committed people. Many are, indeed, "homelike" and "normalized." For people living in group homes, life is richer and more fulfilling than for those in institutions. However, any time you put a sizeable group of people with disabilities together, adding a few staff, you lose the warmth and intimacy that makes a house a home.

If you went to the widely heralded Macomb-Oakland Regional Center in Michigan, Region V Mental Retardation Services in Nebraska, Seven Counties Services in Louisville, Kentucky, or a number of other places around the country, you would hear people talking about new ways to serve people with severe disabilities in the community. While they don't refer to it this way, they are thinking in terms of the nonrestrictive environment. This is

FIGURE 2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TRANSPORTATION
EARLY CHILDHOOD EDUCATION
ADVOCACY

INTEGRATED COMMUNITY SERVICE SYSTEM:
AN ARRAY OF COMMUNITY SERVICES

not a program. It is not a packaged solution to meeting the needs of people with severe disabilities. It is an idea, a way of thinking about how to serve people in the community.

As a concept, the nonrestrictive environment is deceptively simple: find a home for people--with their natural families, with a foster or adoptive family alone or with others they happen to get along with--and build in the supports and services they need to live successfully in the community (cf. Figure 2).

It is easier to define what is not a home than to define exactly what it is. A home is a place where things are arranged according to your own personal preferences and not the needs of a group. A home is where you live with people with whom you have mutual attachments. A home is where you can't be kicked out because you don't fit in.

Families for Children

AMY* AND JIMMY*

> Amy's a girl and Jimmy's a boy. Otherwise they have a lot in common. For one thing, both are eight years old. They both have hydrocephaly and a multitude of associated problems, including blindness, seizures, and hypothermia. Both are tube-fed and are susceptible to choking, infection, bed sores, and sudden drops in body temperature. Fortunately for Amy and Jimmy, they happen to live in states where people are committed to serving children with severe disabilities in the community. Jimmy lives with five other children in a

---

* pseudonym

Medicaid-certified group home just outside Ypsilanti, Michigan. Amy lives with her foster parents, Mr. and Mrs. Parker*, in Lincoln, Nebraska.

Jimmy's house is new and modern and nicely furnished. A single story house, it's fully accessible, with extra-wide hallways, and fireproof. By contrast, Amy's house is rather modest, a small two-story house in a middle class neighborhood. The doorways seem just wide enough for Amy's wheelchair and to leave the house she has to be wheeled onto a mechanical lift.

Jimmy's room, which he shares with another child, is clean. It has two beds, a suction machine, a vaporizer, an oxygen machine, a picture on the wall, curtains on the window, and two dressers. There are half dozen or so toys, and stuffed animals in the room. Amy's room is bright, colorful, warm, and filled with pictures, mobiles, decorations, toys, and statues, in addition to a thermometer and a control device for a heated water mattress on the top of her bed. A cloth red and yellow, handmade "AMY" hangs on the wall by her bed. A radio playing soft music is by her bed. Mrs. Parker thinks Amy enjoys this.

Mrs. Parker spends a lot of time with Amy. She talks to her, gently caresses her, changes her diapers, dresses her, and feeds her. She has to take Amy's temperature frequently, clear her throat of mucous, and change her position in bed. She also provides range of motion exercises. A physical therapist used to come to the house to do this, but Mrs. Parker doesn't think it's a good idea to have a lot of different hands touching Amy. One can see Amy tense up when touched.

The ten or so staff members at Jimmy's house also have to spend a lot of time with him: feeding him, taking his temperature regularly, rotating him, and so on. Staff members can be observed touching and talking to Jimmy and the five other children in the home.

According to Jimmy's house manager, the staff enjoys working at the house. As she sees it, caring for these children in a community setting is not difficult: "These guys aren't hard at all." Similarly, Mrs. Parker doesn't think it's difficult to care for Amy. She speaks with pride when she recalls what doctors said to her when she took Amy in at two months of age: "They said she'd have to be in an institution. I said to myself, 'That's all I need to hear. We'll see about that.' I knew I could take care of Amy and I have."

Mrs. Parker keeps a scrapbook of Amy's progress that she takes out for visitors. She speaks lovingly of Amy as she goes through the pictures, locks of hair, and other momentoes. She also speaks freely of how much Amy has done for her life.

At Jimmy's house, the house manager tries to build in consistency in how staff members handle and treat the children. She reports that open communication and frequent staff meetings are a must.

One senses that Mrs. Parker may be a bit overprotective of Amy. She doesn't trust too many people to provide respite, although she has an older woman come in every once in a while to keep an eye on Amy, but not to do anything for her, so she can go out.

The story of Amy and Jimmy is incomplete without thinking about similar children in institutions. Compared to where they could be, both Amy and Jimmy are doing quite well. After visiting both of them, however, one cannot help but conclude that Amy is doing better.

Amy and Jimmy are as severely disabled as any child at any institution for the developmentally disabled in the country (one would have to go to intensive care or neonatal units at general hospitals to find more severely disabled children). Yet, Amy and Jimmy are exactly the kind of children whom many people think have to live in institutions. If Amy and Jimmy can have their needs met in the community, any child in any institution can also.

Just a few years ago, the "state of the art" in community living for children with severe medical involvements referred to group homes. ENCOR (the Eastern Nebraska Community Office of Retardation) was probably the first service system to serve medically complex children in the community through its "developmental maximation unit" (D.M.U.), located in a wing of a general hospital (the D.M.U. is now a small group home in the community for six children). Today, the "state of the art" is to support these children in natural, foster, and adoptive families. Thus, Macomb-Oakland, which has developed more community living arrangements for people with severe disabilities than any other service system in the country, has stopped placing children in group homes, let alone institutions. As one administrator explained, "There isn't a kid in the world who can't do better in a family than a group home." In the Seven Counties Services Region in Kentucky, children with complex medical needs and "challenging behaviors" are also being matched with foster families. Many of the families have become legal guardians or have adopted. The sentiment that "children belong in a family not in a group home" is echoed here.

Few people would disagree in principle that children are better off in families than in institutions or group facilities. How can good families for children with the most severe disabilities be found?

1. Support the natural family. With very few exceptions, children with the most severe disabilities can live with their own families. As a matter of fact, most children with disabilities always have. Until recently, families were left to care for their children on their own with little help and support. This is changing slowly. Many states and communities are beginning to provide support services to families. We describe some of these services later in this manual. However, supporting natural families means more than simply providing some

respite or home aide services or even financial assistance. It also means aggressive support for the family's relationship with the child.

For a number of years now, advocates for abused and neglected children have argued in favor of their right to a permanent home, whether through adoption or reunification with the natural family (see Knitzer, Allen, & McGowan, 1978). It has taken a while for the concept of permanency planning to make its way to the field of developmental disabilities. The concept is taking hold at Macomb-Oakland and, now, throughout the State of Michigan.

As one Michigan state official described it, "Permanency planning is a fundamental change in the way we do business." It can best be described as a philosophy that endorses each child's right to a stable home and lasting relationships. The thrust is to find a permanent home for every child. As it should be, permanency planning starts with the natural family: provide the services that families need to keep their children at home.

Even with the best support services, some families cannot care for their children at home. This is where the permanency planning approach makes all the difference in the world. In most communities, out-of-home placement signals an end to the family's responsibility for the child. Indeed, many service systems actually discourage family involvement with the child after placement. Permanency planning supports the family's ongoing relationship with the child and aims toward family reunification.

Macomb-Oakland has closed what one person there referred to as the "smorgasboard" of placements commonly presented to families (institution, group home, foster care). For children, there is only one option: foster care. As one administrator stated, "We tell families when they can't care for their children, 'If you're looking for out-of-home placement, we can help you. What we have available is a foster family.'" Parents are approached with empathy and understanding: "We try to break down parents' feeling threatened by foster care. We tell them, 'A foster parent is different. You didn't choose to have a child with a disability, you didn't choose the type of child, you didn't have training prior to having the child, you didn't choose the time of life to have a child with a disability, and you didn't have an out clause. All of that is what makes a foster family different.'"

When a child is placed in foster care, this is viewed as a temporary placement and plans are made to reunite the family. Macomb-Oakland, together with other agencies, develops a written memorandum of understanding with the family and the foster family. This specifies: the reason for the placement, the conditions necessary for the child to return home, the parent's responsibilities to change things to enable the child to return home, the parent's agreement to visit the child regularly, Macomb-Oakland's and other agencies' responsibilities to provide services to families to enable them to take their children home, the foster parent's agreement to encourage and cooperate with parental visits. In short, permanency planning aims at encouraging continued parental involvement during placement with the goal of returning the child to the natural family. When this isn't possible other options are pursued.

2. Find adoptive parents. Adoption is being increasingly viewed as the option of choice for children who cannot live with their families. Macomb-Oakland, Seven Counties Services in Kentucky, and several other service systems around the country are finding parents to adopt children with disabilities. Contrary to conventional wisdom, they are finding that even children with severe disabilities are adoptable. According to Jeff Strully of Seven Counties Services, age is a more important factor than severity of disability in finding families to adopt children. In other words, the younger the child, the easier it is to find adoptive families, regardless of severity of the child's disability.

As part of its permanency planning approach, Macomb-Oakland and Michigan are looking for adoptive families for children whose natural parents are no longer involved in their lives. As Macomb-Oakland administrators describe it, they push hard for adoption for children who do not have involved families. Macomb-Oakland also explores "open adoption" for some children. This is a non-legal arrangement whereby a family gives a child up for adoption, but the adoptive family agrees to cooperate with the natural parents' visits and continuing involvement.

In Michigan, as in several other states, adoptive families can qualify for a range of subsidies, including a foster care payment and either a medical care subsidy or the state's family support subsidy (described later). These subsidies are designed to help adoptive parents pay for the extra expenses entailed in taking care of the child.

3. Recruit and support foster families. Children who can't live with their natural families or adoptive parents should be in foster homes. For some children, foster placement will be a temporary arrangement. Macomb-Oakland's permanency planning approach calls for temporary foster placement until a permanent family can be found (Macomb-Oakland also looks to foster families for adoption). For other children, foster placement is likely to be a long-term arrangement. Even when children cannot live with their natural families or be freed for adoption, they should have the opportunity to live with a family that not only cares for them, but cares about them as well. As part of its permanency planning approach, Macomb-Oakland pursues options known as "shared care" and "permanent foster care" when family reunification or adoption are not possible. Shared care is an arrangement in which the natural and foster parents agree to share responsibility for raising the child; for example, the child might spend weekdays with the foster family and weekends with the natural family. Permanent foster care refers to a nonlegal agreement by foster families to serve as primary parents for children until adulthood.

TOMMY*

There are some very good people in the world. They are caring and willing to commit themselves to the welfare of other people. The best service systems find them. Among many foster families, Macomb-Oakland has found the Remmling* family.

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*pseudonym

Mr. and Mrs. Remmling are a middle class couple with five children ages 5 through 24. They have also been foster parents to three children. One young girl who lived with them has moved on to a group home. They still maintain contact with her. A second child, with severe brain injury and burns covering 75% of his body as a result of scalding in his home, died this past January. Mrs. Remmling and her oldest son, who had taken a special liking to the child, were with him at the hospital when he died. After a brief break from foster parenting, the Remmling's took in Tommy, a frail nine-month old, this spring.

Tommy spent the first several months of his life in a hospital and then a nursing home. Born prematurely in his home, Tommy probably suffered brain injury at birth. Doctors also found traces of alcohol in his bloodstream.

Tommy's got some problems. Since birth, he has had difficulty swallowing. At the nursing home, he was fed through a tube inserted through his nose. This didn't work out too well for Tommy. Bothered by the tube, the infant somehow kept pulling it out. This caused an irritation and then a serious infection. Mrs. Remmling, who visited Tommy several times in the nursing home, speaks with a tinge of bitterness as she describes this: "All they could think about was getting food down him so they could chart it." As a consequence of the infection, Tommy recently underwent surgery to have a gastronomy tube inserted directly into his stomach. The tube is scheduled to be removed in September.

A licensed practical nurse, Mrs. Remmling feeds Tommy 125 cc's of formula every four hours or so. She also says that Tommy needs to be suctioned occasionally with a bulb syringe and "needs to be held." Tommy hasn't adjusted to his new home yet and is still a bit irritable. The biggest problem right now is that he keeps Mrs. Remmling awake most of the night, although she expects this to pass.

According to Mrs. Remmling, she has a "great support system." She receives visits from a registered nurse, an occupational therapist, and a specialist from the public schools, in addition to Tommy's case manager. She also receives 12 hours a week of help from a home aide.

Mrs. Remmling learned about foster care from an ad in the newspaper. She wanted to work and to have the opportunity to use her nursing skills, but with young children, she wanted to stay at home.

> Based on her experience, Mrs. Remmling has a clear sense of what it takes to be a foster parent for children with multiple disabilities and medical involvements: "The nursing experience helps in terms of observation of conditions. But what it really takes is a gut mother feeling. Being a mother prepares you for this."
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> When asked what Tommy gets now that he wasn't getting at the nursing home, Mrs. Remmling had this to say: "Well, first of all, we're going to get rid of that bald spot on the back of his head that he got from lying on his back all the time. The home atmosphere too. You can't replace it." One would be hard pressed to disagree with Mrs. Remmling on this.

"We can't find enough good foster families" is a common lament among agencies. A Macomb-Oakland resource manual (Dewey, 1980) is entitled: "Recruitment of Foster Homes . . .Can Good Homes Really Be Found?" In characteristic fashion, the last sentence of the manual reads: "Yes! They can be found!" Places like Macomb-Oakland have found ways to do what many others say cannot be done.

According to Macomb-Oakland staff, there's a foster parent somewhere for every child. As one administrator explained, "There's somebody for everybody. Foster parents aren't interchangeable though. Some aren't good with kids with behavior problems, but they're good with medically fragile kids.

You have to match the kid with the family. The toughest kid will be taken in by someone who likes him." The best estimate is that Macomb-Oakland has placed 25 children with severe multiple disabilities and medical involvements in foster homes.

So where do you find these wonderful foster parents, these "saints"? First of all, you don't have to be a saint to be a foster parent. To be sure, foster parents should be caring and committed people and willing to treat the child "as their own." According to people at Macomb-Oakland, though, the image of foster parent-as-saint has driven many otherwise good people away from being foster parents. In looking for foster parents, they try to downplay the romanticized version of foster parenting. As long as foster parents are decent people, they don't mind if they are attracted to foster parenting by the opportunity to supplement family income or to practice professional skills. Mrs. Remmling falls into this category.

Second, you have to be prepared to stand behind foster parents. Good service systems offer a lot of support services to foster parents: respite, home aide services, consultation, in home nursing and professional services, and financial assistance for purchasing equipment and supplies and making necessary modifications to a house. Perhaps the biggest support to foster parents is being there when they need some help. This is what good case managers do. At Macomb-Oakland, case managers stay in close touch with foster parents. Part of the reason for this is monitoring foster homes, making sure people placed in foster care are doing OK. It is also a matter of supporting foster parents. As one Macomb-Oakland case manager commented, "I'll stop by during the evening or on weekends. They also know they can call me anytime day or night. You can't just drop in unannounced without reciprocating." In Louisville, Kentucky, another director described how important it was to families to be able to reach someone at the time they need help. As he said, "it is often not important to do anything; just being there and caring seems most important."

Third, it helps if you pay foster parents a decent stipend. For some people, especially those who view themselves as professionals, this will mean the difference between becoming a foster parent or doing something else. Many states and service systems today offer foster parents both a room and board payment and a stipend to provide training and services within the home. Region V in Nebraska recruits both foster parents who receive from $322.00 to 359.50 per month for room and board and "extended families" who are paid an additional $125 to $500 per month for training and services. Macomb-Oakland refers to foster homes as "community training homes" and this creates an expectation of what foster families are supposed to do. Community training homes receive between $25 and $35 per day ($9,125 to $12,775 per year) and higher in some instances. Macomb-Oakland's community training homes serve from one to three people, although it also contracts with some families to operate "alternative family residences" for four people. These homes are provided with an additional budget to hire staff to come into the home. While it is true that many good people can be attracted to being foster parents for children with severe disabilities by the opportunity to supplement family income, it is equally true that some people neither need nor want to be paid a salary for doing what comes naturally; namely, being a loving parent to a child. These people too have to be sought out.

Finally, you have to know where and how to look for foster parents. Places that have been successful in finding foster homes for children with severe disabilities seem to start with the assumption that there are decent people in the world and proceed to look for them. Places that haven't been successful seem to assume that only people who are "just in it for the money" will become foster parents.

Service systems and agencies have used different strategies to recruit foster families: ads, public service announcements, newspaper articles, radio and television appearances, community presentations, newsletters, flyers, posters, and referrals from other agencies and people. Some places have focused on presentations at religious groups and service clubs. Others have relied on the media.

Macomb-Oakland makes foster parent recruitment an agency priority and employs three full-time specialists who recruit and screen foster families. Macomb-Oakland's strategy is to achieve high visibility for foster care. It attempts to generate a large number of phone calls and inquiries in order to come up with a small number of good families. As Nancy Rosenau put it, "What we need to do is generate thousands of inquiries about foster care. You have to get large numbers. Then you need a staff of people to call and stay in touch with them, to nurture and shape them into being able to give what a kid needs." Macomb-Oakland has found that referrals from other foster parents and agency staff, newspaper articles on foster care, and classified ads yield the most foster parents. Macomb-Oakland's recruitment efforts downplay the foster parent-as-saint image and stress the income available through foster care and the opportunity for home employment. Typical classified ads read: "Looking for a new career?" and "NURSES, Your skills are needed in a unique program." Macomb-Oakland officials are only slightly embarrassed by the mercenary tone of its foster parent recruitment efforts. As they see it, their specialists can easily screen out people who are not caring and committed.

"Every child," says internationally recognized child development psychologist Urie Bronfenbrenner (in a personal conversation), "needs at least one adult irrationally committed to his welfare." Bronfenbrenner wasn't referring specifically to children with disabilities. But his words apply to these children just as well. What he was referring to can only happen in a home, in a family.

Supportive Living: Homes for Men and Women

CHARLES* AND PEGGY*

Charles and Peggy live in a trailer in Wahoo, Nebraska, as do some other people in that town. Charles lived in an institution and then a group home;

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*pseudonym

Peggy previously lived in a group home. According to staff, Charles and Peggy did not always get along with other people in their respective group homes. Peggy has some behavior problems. Fortunately for Charles and Peggy, they seemed to get along with each other. So they got married. Their marriage isn't perfect, but this hardly makes them unique. They receive marriage counseling regularly. Their trailer is clean and nicely furnished. Charles planted a small garden out in front and just cut down some weeds in the back.

Charles and Peggy probably wouldn't be doing so well in most places around the country. They would probably be living in institutions or group homes. Left on their own, they would be living in substandard conditions and maybe wandering the streets. They are doing well in Wahoo, however, with support from Region V.

Their trailer is actually a "supervised apartment." Each day a Region V staff member comes in from 2:00 P.M. to 10:00 P.M. (one staff member on weekends and another on weekdays). The staff member cooks for them, makes sure their trailer and small yard are clean, helps them with budgeting and personal hygiene, and works with them on developing skills. He also checks in every once in a while on a nearby trailer where three men live (these men have a staff

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member visit for four hours each day).

Charles and Peggy rent their trailer themselves, although Region V found it for them. It is not simply a "homelike setting." It's their home. They seem very proud of it.

When asked whether people living in their own homes receiving support from Region V ever kick staff out, a Region V administrator answered, "Yes, that happens." When asked what happens then, she said, "Oh, the staff member will go away for an hour or two, and by the time they go back, the people are sorry about the whole thing and apologize."

Charles are Peggy are indeed doing well in Wahoo. Their basic needs are being met. They also have something that too few people with mental retardation seem to have. They are living with dignity.

There comes a point in anyone's life when it is time to leave home. Why is it that people with developmental disabilities have to move from homes to facilities? Why can't they simply move from their families' homes to their own?

It's starting to happen. People with developmental disabilities, even people with severe disabilities, are living in their own homes with the staff support they need to make it in the community. This is called different things in different places. Region V refers to this as "supervised apartments"; Macomb Oakland calls it the "supported living program"; the

Eastern Nebraska Community Office of Retardation (ENCOR) used the same idea in its "alternative living units." We call this supportive living.

Several things make supportive living stand out from traditional service models. First of all, it is a "facility-free" approach. People live in apartments, houses, duplexes, trailers, what have you--and not group facilities.

Second, supportive living means that people receive services and supports wherever they happen to live. In other words, you don't have to live in a licensed facility to get some help. You also don't have to leave your home when you develop independent living skills; staff supports are phased out. Region V has both "live-in" and "live-out" supervised apartments. The "live-out" homes provide staff support for periods ranging from 30 minutes to eight hours per day. Macomb-Oakland describes its supported independence program this way: "The support provided will be based on identified needs, and will cover many areas: rent or living expense subsidy, resource and information referral, transportation, homemaker services, counseling, home health care aide, social and recreational, medical support, and skill building. Staff will be made available on a 'P.R.N.' basis up to twenty-four hours daily, if needed. Utilization of previous supports will be encouraged, i.e. family, employer, advocates, friends."

Third, supportive living is designed, in the words of one Macomb-Oakland administrator, "to leave the bureaucracy behind." In contrast to group facilities, people's homes should not have to be licensed or certified. At Region V, people own or rent their own homes. Macomb-Oakland prefers this, but is prepared to arrange for agencies to rent places on people's behalf. A description of the supported independence program prepared by Macomb-Oakland explains why homes shouldn't be licensed: "It is preferred that these sites be unlicensed, as licensing has several undesirable aspects. Limits would be automatically placed on the type of setting used. For example, single apartments in a building and mobile homes cannot be licensed. Fire marshall and room size requirements would further limit options, as would the distance-between-licensed facilities rule. Licensed facilities must offer twenty-four hour supervision, which would be grossly restrictive for some participants. Lastly, it is provocative to the community to be notified when a foster care license is being issued. It not only promotes community resistance, but it is degrading to the program residents and to be avoided whenever possible."

Finally, supportive living is not just for people with mild disabilities. If it were, it would be neither exciting nor innovative. It is ideally suited for people with severe disabilities and challenging needs. According to Macomb-Oakland, "Behaviorally troubled clients may receive higher quality treatment in a smaller setting. With less competition, as exists in six bed homes, the participant may also feel less need to act out for attention."

Supportive living is a flexible approach to meeting the needs of people with developmental disabilities. The only rule about supportive living is that it has to be individualized. This stands in stark contrast to the traditional way of doing things: design a program (which usually means build or renovate a facility) and then find people to fit in. Supportive living means that you start with the person and his or her needs and then find a home and design the program. Here are some questions to ask.

1. What kind of housing does the person need? Does the person need an accessible house or apartment? What kinds of renovations will have to be made?

2. Where does the person work? It makes sense to find places for people to live which are near or accessible to where they work.

3. Where does the person's friends and family live? You should try to support people's social networks and encourage relationships with family and friends.

4. Should the person live alone or with others? Some people will probably be better off living alone. As Lyn Rucker has written, "People with behavioral needs or severe or profound retardation may need to start with a one-to-one living environment; roommates can be added if it makes sense." Other people, probably the majority, will most likely want to live with others. However, when people live with others, this should be for the same reason that any people choose to live together--because they like each other and get along. Some people might even choose communal (small group)

living arrangements.

5. Should the person live with a family? Like most service systems, Region V, Macomb-Oakland, and other innovative agencies look to families to provide homes for many adults. Region V views its extended family homes as the "model of choice" for both adults and children with severe disabilities. The strength of this is that it enables people to live in typical homes and can foster strong human bonds that are usually missing for people in group facilities and sometimes those living independently. The drawback is that this can lead to a dependent parent-to-child relationship that inhibits independence. It also raises the question of what will happen to people when, later in life, families die. Perhaps the best advice is that anyone placing adults with families should have a specific reason for doing so. A Macomb-Oakland administrator recalled one woman placed with a family who had grown up in an institution and longed to live with a typical family. Finally, it should be pointed out that "family care" can be a flexible and individualized approach. Region V views its extended family homes this way. These include not only traditional families who accept people into their own homes, but also roommates who are contracted with to provide training to a person in a shared apartment.

JOHN*

> At Macomb-Oakland, the supported independence program is just now getting under way. The first person served in this program will be John. John, who has multiple disabilities including severe physical involvements, had been living with his parents until they died recently. Other family members now own the home. John will continue to live there with support from Macomb-Oakland. Macomb-Oakland will pay for 24-hour per day staff support, home maintenance, and other living expenses. These services will cost approximately $120 per day, a figure comparable to Macomb-Oakland's "AIS/MR" facilities. In the long-run, people at Macomb-Oakland think this approach will be less expensive.

People with severe disabilities have a lot of needs. They have some "special needs." They may need staff support, medical assistance, and special programming. But they also have human needs. In attempting to address their special needs, we've overlooked these. All people, regardless of disability, need a warm and pleasant place to live, companionship and friendship, and respect and human dignity. Everybody needs a home.

Build in the Supports

Instead of developing facilities, we should be thinking in terms of the services and supports people with severe disabilities need to live in typical homes in the community. In other words, put resources into services, not buildings.

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*pseudonym

For people with the most severe disabilities, the array of services necessary to make it in the community may be extensive. Young children may need early childhood education and infant stimulation; school-aged children will require special education; older children and adults will need vocational training and employment supports; practically anyone with a disability may need legal or advocacy assistance. For people to participate fully in community life, all of these services have to be in place. When it comes to living in community homes, people with the most severe disabilities, or the people who care for them, are likely to need the following kinds of services and supports.

1. Family supports. When we say that all children belong with their families, we are not suggesting that families should have to "go it alone." Just as we should not expect foster families to be saints, neither should we have this expectation for natural families. As we have suggested throughout this manual, natural families should be supported with the same services available in out-of-home placement.

In looking for good ideas for serving people with severe disabilities in the community, we have identified three innovative approaches to supporting families. Each offers its distinct advantages. The approaches are not mutually exclusive and, in fact, can be used together to meet families' needs more effectively. In Michigan, which has made family support a priority, as suggested by its permanency planning, one can find a combination of approaches used together. The first approach is the family subsidy. A number of states now have family subsidy programs. Michigan is one of these. In Michigan, the state pays direct cash subsidies to families of children with severe disabilities. The subsidy is designed to help parents pay for the extra expenses incurred in having a child with severe disabilities (for example, equipment, respite, home renovation, diapers, sitters). The subsidy amounts to $255 per month, an annual subsidy of $2,700 for eligible families.

Passed by the Michigan legislature with strong support from parent and advocacy groups, the Family Subsidy Act appealed to people with diverse political persuasions ("liberal," "conservative," "right-to-life"). As an economic measure, supporters argued that passage of the legislation would result in cost savings to the state by preventing out-of-home placements and encouraging families to take their children home from institutions and nursing homes. As a philosophical rationale, they pointed out that the legislation supported traditional family values.

Some agencies were not supportive of the legislation. They took the position that families would be better off by providing the funds to the agencies to operate family support programs. They also questioned whether families might use the funds for other things not related to their children with disabilities. Supporters countered that families themselves were in the best position to determine their needs. As one of the key legislators supporting the Family Subsidy Act put it, "We made the assumption that families are capable of making good decisions." It might also be argued that even if families used the subsidy for general household expenses, this can make it easier to maintain their children at home.

The eligibility criteria for Michigan's family subsidy program are as follows:

1. The family's annual income must be less than $60,000.
2. The child must be 0 to 18 years of age (after that age, they are eligible for Supplemental Security Income).
3. The child must have a severe disability. This includes children with severe mental impairments, autism, and severe multiple disabilities, as identified by public schools in accord with state education law. Thus, the family subsidy program is tied to public school criteria for determining level of disability. This relieved developmental disabilities agencies of the responsibility for making difficult individual eligibility decisions. Since children are already labeled by public schools, there is not as strong an incentive to define children as eligible who were not designed to benefit from the legislation.

As with any "categorical" program targeted to a specific population, the family subsidy program creates potential inequities in terms of beneficiaries. Families of children with severe physical disabilities and moderate mental disabilities are not eligible for subsidies. Surely, many of these families incur extraordinary expenses in caring for their children at home. Yet the Michigan Family Subsidy Act is an important step in the right direction. The program encourages, rather than discourages, families to maintain their children at home, reversing the traditional pattern of developmental disabilities services. Over 2,000 families participate in the Family Subsidy Program throughout the State of Michigan.

The second innovative approach to family support services is modelled on a "voucher system." This is used by Community Services for the Developmentally Disabled, a community mental health center in the Clinton-Easton-Ingham counties area of Michigan. Under this approach, families are provided with an allotment with which to purchase one or more types of respite from a "menu" of services. Community Services for the Developmentally Disabled provides families with $255 worth of respite per quarter (every three months), in addition to family subsidies from the state. With this allotment, families can select the following services:

1. Foster Home Respite Care. Respite care is provided in licensed foster homes by providers who are trained individually to work with the child. After training is provided, the family makes arrangements with the provider directly. This service costs $20 per full day and $10 per half day (six or fewer hours).
2. Home-based Respite Care. This is respite care provided in the home by a part-time C.S.D.D. employee who is trained to work individually with the child. Arrangements are made directly with the worker. This

costs $4.50 per hour, up to 16 hours per day.

3. Family Friend Respite Care. This is respite care provided by a person selected by the family and paid $2 per hour with a maximum of $15 per day.

4. Drop-in Day Care Center. This is a "first come, first served" drop-in center operating on Saturday from 8:00 A.M. to 10:00 P.M. Eight spaces are available. This cost $2 per hour.

Families may be able to exceed their quarterly allotment in the case of emergencies if they receive prior approval. Families can also use their own funds to purchase additional respite care services.

What makes this program exciting and innovative is that it allows families to select the type of respite they want. It places control with the family, rather than with an agency.

The third general approach might be termed, "You tell us what you need and we'll try to get it for you." This is a flexible approach tailored to families' needs. It requires an open-ended budget and a commitment to purchase anything that will make it easier for the family to care for the child. As part of its permanency planning, Macomb-Oakland also has funds set aside to put into place an individualized family support program for families with extensive needs. The services that might be offered include not only respite and hcme aides, but also medical and adaptive equipment, counseling, parent training, modifications to the home, in-home nursing, and others.

In addition to these general approaches to family support, there's an incredible number of different types of family support services offered in different places: parent-to-parent mutual support; sitter-companion services (coordinator matches families with individuals); direction services (personalized information, referral, and follow-up support to match families with the services they need); parent respite cooperatives; social-recreational aides (the best ones integrate people with disabilities into generic services such as YMCA or YWCA).

To provide respite, some agencies have developed respite facilities or earmarked "beds" in group homes for respite. Both of these arrangements have disadvantages. Respite facilities are usually underutilized at some times (for example, weekdays), but can't meet the demand for respite at others (weekends or summers). Since they have to be maintained whether or not they are used, they usually aren't cost-effective. Group home beds set aside for respite have a way of being used as a permanent placement.

As an alternative to respite facilities or group home respite, Macomb-Oakland and other agencies look to foster homes to provide respite to families. Families are paid the community training home per diem for each day of respite. Macomb-Oakland is working on an arrangement for respite care whereby families would receive four weeks of pay for providing three weeks of respite. This will carry a "no reject" clause; in other words, families will have to agree to accept anyone referred to them for respite.

When thinking about family support, it is important to keep in mind the needs of adoptive and foster families. Like natural families, they may need a range of supports to care for children with severe disabilities.

2. Staff Support. As indicated earlier, people with the most severe disabilities are not likely to live independently. Some commentators also point out that few, if any of us are truly independent.

In many places, you have to live in a facility to receive support from staff. You can get 24-hours-a-day support or no support. This doesn't make sense. People should get the support they need, in the amount they need, wherever they happen to live.

What makes innovative approaches like Region V's supervised apartments work is flexible staffing arrangements. Some staff members live with people; others drop in for a half an hour or several hours a day; others are there for eight hours a day to make sure people get important things done. Similarly, Macomb-Oakland's supported independence program will provide staff support ranging from a few minutes a day to 24-hours a day.

In discussing individualized placements in community homes--living alone or with a small number of others, one is always confronted with the question of cost. Isn't it more expensive to staff a home for one to three or four people than a group home for six, eight, or twelve? The honest answer to this question is that no one really knows. No studies have been done on this. However, both Region V and Macomb-Oakland maintain that their supervised apartments and supported independence program will be no more expensive than group homes, especially ICF/MR facilities.

The question of cost must be approached in terms of an entire service system. That is, cost should be examined for serving all people with disabilities in community homes as opposed to group facilities. First, all children should be in natural, foster, or adoptive homes. No matter how intensive the services provided to support families, this will be much less expensive than institutions or group living arrangements. Second, some adults can and should live with families or, as in the case of Region V's extended family program, with roommates who are contracted with to provide support and assistance. This too is less expensive than group living arrangements. Third, many people currently living in group homes don't need the 24-hour-a-day staff support they receive. They only need someone to drop in on them from time to time or to come into their homes for a limited number of hours per day. For these people, it will be less expensive to serve them in their own homes than in group facilities. Fourth, it's an illusion that institutions and group facilities are inexpensive. Indeed, many "behavioral units" and "medical facilities" are incredibly expensive. Many facilities are, in fact, overstaffed in the sense that many staff members are doing the work that fewer could do; the staff interacts with each other, rather than the people living there. In short, people with the most severe disabilities are expensive to serve, no matter where they live. Having said all of this, it is no doubt true that for some people, the costs may be higher to serve them in community homes than to place them in group facilities. So will the benefits.

3. Professional Supports. For some people with the most severe disabilities, it takes professional know-how to serve them well in the community. For example, people with multiple disabilities and medical involvements may need medical and therapy services; people with behavioral involvements will need intensive and consistent programs. How can these needs be met in homes dispersed through the community? Integrated public school systems face the same problem. How can you provide physical therapy, occupational therapy, and other related services in regular schools dispersed throughout a geographical area? The State of Vermont, the Madison Public Schools, and other educational systems solve this problem by using professionals as consultants in an interdisciplinary or transdisciplinary team (Taylor, 1982). Instead of providing physical therapy to a child one-to-one for an hour or two a week, for example, physical therapists consult with and train teachers to integrate physical therapy into the special education curriculum. Macomb-Oakland, Nebraska's Region V and other community service systems are using the same approach to meet the needs of people with severe disabilities living in the community.

Use professionals to consult with, train, and support families and staff. You seldom, if ever need round-the-clock professional staffing to serve people with severe disabilities in the community (institutions almost never have this either). What you do need is a core of nurses, physical therapists, behavioral specialists, and other professionals: to help staff design individual programs; to train staff in range of motion exercises, tube-feeding techniques, the use of equipment, nonaversive behavioral interventions, and other approaches; to model techniques and training approaches in the home and other community settings; to monitor programs; and to be accessible day or night when needed.

Macomb-Oakland employs 55 professional staff, in addition to contracting for $3/4 million in professional services. Macomb-Oakland's professional support services include nurses (1:48 ratio), psychologists (1:60 ratio), physical, occupational, and speech therapists (1:240 ratio for each), dieticians (1:500 ratio), two physicians who do not provide primary medical care, and a sex educator. To serve people with challenging behaviors, Macomb-Oakland psychologists provide training and consultation to private nonprofit agencies that run services. Macomb-Oakland also has a budget of $1.5 million to provide one-to-one staffing for people with challenging needs (this staffing is given to agencies on a three-to-six month basis). In terms of medical needs, Macomb-Oakland distinguishes between high, medium, and low "consuming" clients who receive weekly, monthly, or quarterly visits from nurses. All people are served by community physicians. Macomb-Oakland nurses are responsible for identifying receptive physicians in the community. As a matter of philosophy, Macomb-Oakland believes in using generic community resources for professional services. As one administrator explained, "Anything and everything I can get through the community, I use. If no one else can do it, we play a direct role." Macomb-Oakland must obtain civil service approval to use generic agencies for professional services and has worked out a detailed procedure to contract for services.

Region V is also looking to generic providers for professional services. It draws on independent consultants from a local university to design behavioral programs. According to administrators, this independence enables consultants to develop programs that are truly in people's best interests. While these behavioral consultants sometimes offer staff training sessions, they spend most of their time in homes consulting on programs for individuals.

4. Equipment and Devices. There's something about medical equipment and devices that makes people think they can only be found in institutions. It's unfortunate, but true, that some people with severe disabilities have had to live in institutions simply because equipment wasn't available in the community. For people with severe disabilities and medical involvements, a range of equipment may be necessary: suction machines, apnea alarms, oxygen, vaporizers, temperature control devices, mechanical lifts, and others. These have to be available to families, foster families, and staff; of course, people must also be trained how to use them.

5. Case Management. Call it case management, direction services, case coordination, or what you will, somebody has

to be responsible for making sure that people with severe disabilities are doing OK in the community and are receiving the services they need. The more dispersed people are throughout a community, the more important this becomes.

A few things are important to note in discussing case management. First of all, case managers, or others playing the same role, must have a manageable case load. In some places, case managers are supposed to relate to as many as 40 or 50 people living in the community. You can't give people what they need when you have this many to serve. Macomb-Oakland case loads range from approximately 20 to 25 people. Second, case managers should have a measure of independence from people who provide direct services. It's difficult, if not impossible to monitor services and living arrangements when you're beholden to the people operating them. At Region V in Nebraska, case managers report directly to the regional office, rather than local area agencies that provide services. Similarly, Macomb-Oakland's case managers, who are expected to play an aggressive monitoring role, are separate from contract service providers. Finally, case managers should play a flexible role. A good case manager doesn't just work 9:00 to 5:00 on weekdays or assume a rigid role. A good case manager does what people need to have done, when they need to have it done.

COMMUNITY INTEGRATION: MORE THAN A NICE PLACE TO LIVE*

Again and again as we talked to service providers across the country we heard that community integration doesn't just mean living in a home in the community. It also means participating fully in community life--playing, going to school, shopping, and in the same places as other people. We continually heard that people's lives can't be chopped up into little pieces: If one part of a person's life continues to restrict integration then the entire quality of life suffers. A constant concern of the most innovative residential providers was the nature of the vocational opportunities available to the people they served.

Like residential services, vocational services have traditionally been conceptualized in terms of a continuum from the most to least restrictive placements. Ideally an individual is seen as moving from day treatment and training centers through sheltered workshops to competitive employment. But the ideal is hardly the real. Even for people with relatively mild disabilities, sheltered employment has become a dead end street. Of course, people with severe disabilities almost always end up on the restrictive end of the continuum in facilities that focus on teaching "ADL" (Activities of Daily Living) and "prevocational" skills and provide no opportunity for regular interaction with non-disabled people other than staff. As a way of designing services, the vocational continuum suffers from the same pitfalls as the residential continuum.

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*Special thanks to Jan Nisbet and Mike Callahan for their suggestions for this section.

Spurred by the public schools, vocational services are changing slowly. For the past several years, public schools in Madison, Wisconsin; DeKalb, Illinois; and other places across the country have been placing students with severe disabilities in integrated job sites (Taylor, 1982). As students are graduating from many of these school systems, they are moving into nonsheltered vocational placements. For example, recent graduates of Madison's programs for students with severe disabilities have all moved on to work in integrated settings. In short, the public schools have provided a base of experience in integrating students with severe disabilities that has called into question the need for segregated vocational and prevocational settings.

Based on the growing experience of the educational system in community-based instruction of people with severe disabilities there is an emerging consensus that traditional segregated day program, sheltered workshops, and other segregated models are inappropriate for everyone. As Lyn Rucker has written, "The workshops of today are rapidly becoming a dead end placement for most persons with mental retardation regardless of their functioning level. It is critical to integrate persons so that they can learn real work skills in a real work environment."

Vocational agencies like New England Business Associates in East Hampton, Massachusetts and Community Work Services in Madison, Wisconsin which are on the frontier of the development of new vocational services have one clear message for those who would follow their lead: Don't buy a building! A vocational agency needs an office--like any other employment service. Actual services are provided at job sites in existing industries or other community settings. The support personnel go to the workers not vice versa. This end to the specialized vocational facility is the one element which is common to all the otherwise disparate models of integrated vocational services which are developing around the country.

The "state of the art" in integrated vocational services is still evolving. New program models--ways of supporting people in employment--are being developed. These are moving in the direction of more integrated and individualized placements which are considered the optimal means for providing vocational opportunities for persons with severe disabilities.

Individual Job Placements.

The most integrated way to serve people with developmental disabilities is to find them jobs in regular industries and businesses. At a growing number of places across the country, people with severe disabilities are working alongside typical people. The nature of their work varies. Sometimes people hold the same jobs other people do, although they may perform them at a different pace. Or they may perform specific tasks associated with a larger job.

The key to placing people with severe disabilities in regular work settings seems to be the match between the worker and both the work and the setting. Some settings, especially industries that don't deal with the general public, can tolerate a high level of "different" behavior. Even people with the most challenging behavior can fit into these. This has been the experience of Community Services for Autistic Adults and Children, which has placed a sizeable number of people with autism into regular work settings.

There are several ways to support people with severe disabilities in regular work. One is to pay for trainers to work with one or a small group of people at regular settings with the goal of phasing out the trainer over time as people learn to work independently. Macomb-Oakland used this approach and has found that the costs of doing this are comparable to those in segregated day programs (increased staffing costs are offset by savings in building costs and overhead). A second approach is to look, subtly, for typical people to take severely disabled people "under their wing." Lou Brown, who looks to small, family businesses as job placements, talks about this. A third way is to pay, through agency funds, a coworker to provide ongoing support, training, and assistance to the worker with a severe disability.

Macomb-Oakland began placing "unemployable" people in community work sites in 1983. Today, Macomb-Oakland supports a number of people in individual job placements. These include at least some people with severe and profound retardation and behavioral involvements. People work from two to 40 hours per week at places such as parks, offices, factories, restaurants, gas, stations, and other small and large businesses.

According to Mark Maxwell, Macomb-Oakland's vocational director, it takes a lot of business savvy to place people in community jobs and this is what most vocational programs lack. As he describes it, you have to know how to sell business on the benefits of hiring people with disabilities and understand what tax credits are available to employers. He also says that finding community jobs for people with severe disabilities requires a systematic approach.

Strategies for Achieving an Individualized and Integrated Vocational Service System

Efforts to move people out of segregated environments have resulted in the development of enclaves, mobile job crews, and benchwork assembly models. While they are a step in the right direction, these employment approaches remain closely related to the traditional sheltered model. They should be viewed solely as means for moving the vocational service system towards a fully integrated and individualized model of service. These vocational services are integrated in the sense that they are located in competitive industries or community locations. The distinctive characteristics of these approaches include: a) the people with disabilities are employees of the services agency, b) they work together in groups (often quiet large) and, c) they are supervised by employees of the vocational services agency. Some of the specific models included in this group are enclaves or workstations in industry, community job crews, agency owned businesses, affirmative industry (i.e., at least 50% of the workers have a disability), time-limited work experiences, and sheltered workshops in community sites.

Job crews, in particular, are becoming an increasingly popular example of this type of vocational strategy. A job crew is simply a small group of people who perform regular work. Examples include a groundskeeping crew at local parks and carpet cleaning services working in local homes and businesses.

Donald*

> Region V in Fairbury, Nebraska has developed a two-person staffed job crew with the local parks and recreation department. During the summer, they work as groundskeepers at area softball and baseball fields. So do some nondisabled workers. One of the two people in this job crew is Donald. Donald strikes one as retarded and autistic. He seems shy and a bit withdrawn. Donald, who grew up on a farm, came to Fairbury from an institution. One of his jobs is to "drag" the fields in a tractor. A staff member gives instructions to him, but Donald seems adept at driving the tractor in concentric circles until all of the field is dragged. The scene of a man with this level of disability driving a tractor is striking. It is striking not because there is anything inherent in mental retardation or other developmental disabilities that would prevent someone from learning how to drive a

tractor. It is striking because Region V in Fairbury came up with the idea of letting him try.

Like all of these vocational strategies job crews provide more opportunities for integration then sheltered workshops. But, they are not integrated in the true sense of the word. People may be doing "real work" but they frequently do not interact with nondisabled coworkers.

Some vocational approaches are based on a training model which assumes that during short-term experience an individual will develop the skills needed for regular-employment. These time-limited work experiences are always located in integrated community sites. This approach to integrated employment includes:

a) Training jobs which are designed to teach general and specific workskills to be used on another permanent job after the training is completed. These jobs are agency negotiated. The worker may be paid by either the agency or the employer.

b) Rotating work experience means each employee is moved through a variety of integrated work settings which are designed to provide a wide range of work experiences. These slots are negotiated by the agency. And as in a training job either the agency or the employer may pay the worker.

c) Volunteer training positions are situations where an employee performs unpaid work in an integrated setting for a specific purpose. Usually this is used to demonstrate that a person with a severe disability can develop job-skills and function in the work place. The agency should use this as a last resort, have the employee's agreement, and negotiate specific timelines and expectations for after the completion of the voluntary period.

Where and with whom people work affects interactions and relationships. Currently, there is a debate regarding the concept of "work as a means of achieving integration." Bellamy and his colleagues (1984) believe that the wages earned can affect integration. A sufficient amount of money can buy entrance to integrated sporting events, community environments, stores, vacations, which ultimately allow a person to interact with nonhandicapped persons. Therefore, where one works becomes less important than the amount of money earned. Brown and his colleagues (1984) have a contrasting argument. They believe that the value of working in an integrated environment must be seen as important as the amount of money earned. Interacting with nonhandicapped persons in the workforce on a day to day basis will ultimately create important relationships which lead to further community integration in addition to altering the perceptions that severely disabled person must function in sheltered environments. Severely disabled workers should be reimbursed for their productivity but not at the expense of integration.

In summary, integration does not mean only physical proximity to nondisabled workers. It means severely disabled workers working alongside of and sharing responsibilities with nondisabled co-workers; taking breaks, and having lunch with their nondisabled peers; receiving instructions from the company supervisors and learning from their nondisabled co-workers; and being a valued employee of the company.

MAKING COMMUNITY INTEGRATION WORK

What makes community integration work? That is, what distinguishes good integrated programs from bad ones? Why is it that some places do a good job of serving people with the most severe disabilities in the community, while others don't serve these people at all?

There are professional and technical answers to these questions. To be sure, the best, most integrated programs have the technical know-how they need to serve people in the community. If you're placing people in the community, you'd better know how to fund the supports they need to live successfully. If you're serving people with medical involvements, you'd better be sure that staff or families are trained in how to use medical equipment and adaptive devices, how to recognize medical warning signs, how to feed, handle, and position people, and how to deal with other matters. Similarly, if you're serving people with challenging behaviors, you should know how to implement non-aversive behavioral programs. These and other things you should know.

Yet it would be misleading to portray community integration simply as a technical matter. It is not. While professional and technical expertise may be important, it takes more than this to make community integration work.

1. Commitment. When you take a close look at the best, most innovative service systems and agencies--those that serve people with the most severe disabilities in integrated community settings--you find a common strand that ties them

together: a deep commitment and belief in what they are doing. Commitment is the key to community integration.

At Macomb-Oakland, Region V, the Working Organization for Retarded Children in New York City, and Seven Counties Services in Kentucky, people are committed to a philosophy and a vision of what services should look like. The philosophy and vision may vary somewhat from place to place. As an agency, Macomb-Oakland is driven by the goal of getting everyone out of institutions and into the community in the shortest possible time. This is what Jerry Provencal, Macomb-Oakland Director, refers to as a "sense of urgency." As he described Macomb-Oakland, "What we have done best is to serve a large number of people in the community in a short period of time." Region V is committed to social integration, the fullest possible participation of people with developmental disabilities in community life. This is why Region V has adopted the goal of becoming a "facility-free" service system. At Seven Counties Services, people emphasize the importance of developing relationships with people with disabilities. From this vantage point, it is not enough to serve people in the community or even to integrate them into community life; people also have to make a personal commitment to people with disabilities and develop mutual relationships with them. For the Working Organization for Retarded Children, a relatively small agency which serves people with severe, multiple disabilities in ICF/MR-certified apartments, the mission is to offer the most normalized services possible given state-imposed bureaucratic and regulatory obstacles.

Broad-based commitment doesn't happen on its own. This is where leadership comes in. You don't have to have a charismatic leader to have good services (although this doesn't seem to hurt). However, you do have to have competent and committed administrators who can set a direction and support and reward staff members who follow that direction.

At Region V and Macomb-Oakland, administrators talk about the need for all staff members to feel "ownership" over what they do. As Region V's Executive Director explained, "You have to respect the staff. They have to feel ownership of what they do. If you don't own it, you won't do it." Thus, all staff members are involved in goal-setting and monitoring services. Similarly, Macomb-Oakland administrators are the first to admit, though, that not everyone shares the same exact philosophy and principles. As a state agency, Macomb-Oakland has a number of long-term civil service employees who may not subscribe to the direction set by the administration. According to administrators, it isn't necessary for everyone in the service system to share the same vision. As they see it, it takes about six hard-working and highly committed people in key leadership positions to make a service system work.

2. Flexibility. The best service systems and agencies allow for flexibility, creativity, and innovation. Practically, everyone agrees that services should be individualized. The problem is that they almost never have been designed this way. As we have argued, the services should fit the person and not vice versa and this requires a degree of flexibility.

How do you build in flexibility in a service system? Perhaps the only way is to decentralize decision-making. As they say in Nebraska, "place control as close as possible to the individual being served." No matter how competent or committed, somebody remote from the people being served cannot make decisions about where and how they should be served. You can establish principles, set standards, and establish safeguards, but you can't do right by a person unless you know the person.

In looking for "model programs," we have found that places that integrate people with severe disabilities into the community fall into two categories. The first includes places where good things seem to happen despite the service system. In many states, you can find small agencies, composed of committed and creative people, who find ways around bureaucratic requirements in order to provide individualized and integrated services. This doesn't seem to be the way to design things, simply because not all agencies are staffed by equally committed and competent people. The second category includes service systems that have a built-in degree of flexibility. Macomb-Oakland, Region V, ENCOR, Seven Counties Services, and many others fall into this category. As a state-operated agency, Macomb-Oakland may be somewhat of an anomaly. Most state agencies do not seem to have anywhere near the degree of flexibility that Macomb-Oakland has. The Michigan Department of Mental Health seems to support Macomb-Oakland's direction and gives it more autonomy than agencies in most states. Macomb-Oakland administrators, in turn, seem to reward and encourage staff creativity and initiative. We'll return to the case of Macomb-Oakland later.

If we were to design a service system to maximize flexibility, without sacrificing accountability, we would probably do so along the lines of the Nebraska system. Nebraska's six community mental retardation services regions are independent of state government. The state establishes regulations and funnels, but not controls, funds to the regions. Each region is controlled by local counties, each of which has a representative on the multicounty governing board.

There may be disadvantages to this set-up. For one, since the state does not control the regions, this can lead to a lack of state support, and hence funding, for community services. Further, regional community service systems cannot access funds allocated to institutions. Finally, as people at Macomb-Oakland point out, locally controlled service systems may water down the political voice of the disability constituency and may be more susceptible to political tides opposing community integration (although this seems less of a possibility in multi-county regional systems than county systems).

The advantages of regional control over services seem to outweigh the disadvantages, however. First of all, regional systems are usually free of the cumbersome bureaucratic obstacles that characterize many state service systems. Regional control seems to allow for greater flexibility. Second, regional systems seem more accountable to the people being served. Decision-making is based not in a remote and faceless bureaucracy, but in people's home communities. Third, at least in Nebraska, local elected officials actually seem to feel a stake in services. It is a matter of "taking care of their own" (a sentiment many people in Nebraska characterize as a Nebraska value, but one which, one would hope, is shared by people elsewhere). All of this stands in stark contrast to many states in which "deinstitutionalization" is viewed as a state policy rudely thrust on unsuspecting communities.

Consistent with placing "control as close to the individual being served as possible," Nebraska's regions have moved to an "area management" system. Each region is sub-divided into smaller management units corresponding to one or more counties. These areas have their own directors. While the regional office sets policy, establishes general procedures, implements monitoring and evaluation systems, and approves area budgets, the areas seem to have a great deal of flexibility in designing services to meet individual needs and fit with local circumstances.

This area management system seems to have a lot to do with what makes Region V an innovative and responsive community service system. The area agencies are "humanscale" organizations, especially in rural communities. They are relatively small and manageable; one of Region V's areas serves 28 people. This insures that decisions about people are made by staff who know them personally. Area agency staff also seem to have a strong sense of identity and, hence, feel "ownership" over what they do. This contributes to the high level of commitment found at Region V. Finally, when one visits Region V area agencies, one senses close ties between the area agencies and the local communities. Area agency staff live in and know the local communities. While many states are moving toward regional systems, most place responsibility for the operation of community services with state agencies or local counties. This isn't likely to change in the near future, if at all. Macomb-Oakland's experience is instructive. According to people there, the State of Michigan wasn't committed to community services when Macomb-Oakland was getting off the ground: "We had to persuade them to let us try new things. We talked them into giving us autonomy." Macomb-Oakland created its own momentum. It won the flexibility it needs to try new ideas and models.

3. Accountability. One of the things that distinguishes successful programs, those that are integrating people with severe disabilities into the community, from unsuccessful ones is a willingness to be subjected to independent review and consumer evaluation. Places like Macomb-Oakland, Region V, and Seven Counties Services seem to welcome external review. This has a lot to do with the quality of their services and their openness to innovation and change.

All services should be subject to independent evaluation. The history of institutions teaches us what can happen when places are out of sight and out of mind. When you serve people in dispersed settings throughout the community, it is just as important to keep a close eye on how people are doing. As bad as it might be, you can always go to an institution to see what things are like. Once you move people into the community, the danger is that no one will know how they are faring.

Practically every state has established certification procedures for services. Federal laws and regulations often require these. Institutions and community settings alike undergo life-safety inspections, fiscal audits, compliance surveys, professional reviews, utilization reviews, and a host of other licensing and certification requirements. These formal surveys and reviews yield certain kinds of information. They might tell you if a facility meets fire codes, if the record-keeping and paperwork is in order, and maybe if people are involved in some kind of programming. But they never tell you about the quality of life and degree of integration. For this, you have to go to the people whose lives are affected by the services.

Consumer Monitoring. Some agencies seem to resent external monitoring of their services. Many objections are raised to keep out outsiders: "We have to respect clients' confidentiality," "It's too disruptive," "We're already licensed and certified," "We can't let people visit because these are people's homes." By contrast, Macomb-Oakland welcomes external monitoring.

Since 1980, parents have been monitoring Macomb-Oakland group homes under the auspices of an external advisory committee. A core committee of six to eight parents coordinates the monitoring; as many as 25 additional parents may be involved in visiting the group homes. The core committee meets monthly, prepares monitoring reports, and makes recommendations for changes in group homes.

In monitoring the group homes, parents do not use survey forms and instruments. Their role is not to assess compliance with standards or to review individual clients. Rather, they evaluate "the 'feel' of each home; its appearance, atmosphere, warmth and overall sensitivity to important areas in the home's operation and the resident's well-being."

In support of parent monitoring, Macomb-Oakland provides parent photo identification cards (parents visit unannounced), pays mileage costs for trips to group homes, and provides parent monitors with office space, a telephone, postage, stationery, and photocopying. Parents are not paid for monitoring.

While parent monitors try to visit every group home at least every two months, some homes are visited less frequently.

Consumer Advisory Committees. Consumer advisory committees are another way of building in external review and consumer involvement. Many agencies have established external advisory boards. What makes some places stand out is that they actually solicit advice and take it seriously when given.

Program Review Committees. These are external committees, which include consumers and parents, that review all programs that might involve a restriction on people's rights. Region V maintains an external program ethics committee. According to committee members, Region V has never gone against the committee's recommendations. Committee member's biggest complaint about Region V is that the administration and staff sometimes bring cases to the committee that do not involve restrictions on people's rights. In other words, Region V errs on the side of being too cautious, a commendable trait for an agency.

System Review. Region V undertakes a thorough and lengthy annual "systems review." Region V has been accredited by the Accreditation Council for Services to the Mentally Retarded and other Developmentally Disabled since 1978. In fact, in 1974 one of its area agencies, Saunders County Office of Mental Retardation (SCOMR), was the first community service system in the country to be accredited. Yet Region V doesn't feel the accreditation system goes far enough in guaranteeing a high quality of services and a high degree of integration. As they explain it, they feel that accreditation standards focus too heavily on paper compliance and ignore many aspects that they feel are important. So Region V developed its own review procedures which focus on both record-keeping and people and programs. As part of this annual review, Region V surveys parents and consumers on what they like and dislike about its services.

Commitment, flexibility, and accountability--these things, and not just technical expertise, are what make community integration work. In fact, if you have these characteristics, you can often figure out how to solve the most challenging technical problems. As Jerry Provencal put it, "The answers are easy; the work is hard."

MAKING LIVES BETTER WHILE DEVELOPING GOOD SERVICES

In preparing this manual, we talked to a lot of people about what community integration means. We looked for people who were committed to community integration in the first place. Not surprisingly, we found that it is easy to get agreement on basic philosophy and principles. If you're committed to community integration, you're likely to agree with all of the principles we listed earlier in this manual. However, we found that there is one issue on which people equally committed to the rights and well-being of people with severe disabilities disagree: is the mission today one of developing *only* the highest quality, most integrated services or is it one of ending the suffering of people in institutions and preventing other people from having to live through the institutional experience?

This issue can be framed more concretely. Throughout this manual, we have argued that *everyone*, including people with the most severe disabilities, needs a *home*, not a "homelike" setting, or a natural environment, or a group facility, but a true home. For children, this means living with a family; for adults, this means living alone or with a very small number of other people in a house, apartment, or other place where typical people live. Is this a vision of what services should look like--something we should work towards--or is it a yardstick for practical day-to-day decision-making? Put bluntly, if you believe that everyone needs a home, can you justify developing group homes if this means that you can get people out of institutions more quickly? This is the controversy.

Some people believe that you only develop the highest quality and most integrated services, no matter what. For example, you should only place children with families and adults in small supportive arrangements in typical community homes. As a corollary to this belief, if you can't develop the best services, don't develop any services at all. If, for example, funding mechanisms prevent the development of individualized placements or if caring and committed families cannot be found for all children, then people will have to remain in institutions or go unserved in the community.

Many other people just as passionately believe that the mission is to return everyone in institutions to the community in the shortest possible time. Jerry Provencal, Macomb-Oakland, Director, warns against what he calls the "purist trap," the belief that only ideal services should be created. As he and others at Macomb-Oakland argue, they will not let their inability to develop the most normalized or integrated services stand in the way of developing a large number of community placements. They readily admit that they operate too many group homes and sheltered workshops, but they don't apologize for these. They developed them to get people out of institutions. Today, Macomb-Oakland is moving towards more integrated and individualized services; it no longer places children in group homes, let alone in institutions, and is developing the supported independence program for adults. If, however, it had to develop all of its group homes and sheltered workshops again, it would readily do so.

As with any philosophical issue, there is no "right" answer in this controversy. If we were pressed to give our own answer, we would be inclined to say that both sides are right. Having looked at some of the best group facilities and home and family-based services in the country, it would be a philosophical compromise to suggest that group homes should be developed, especially in the case of children. Just as surely, though, having looked at many institutions, it too would be a philosophical compromise to suggest that some people had to continue to live there because we can't develop the best services quickly enough. How can you explain to people living in institutions and their families that staying there is better than living in a small group home in the community?

It's up to you to decide where _you_ stand on this controversy. If, on the one hand, you believe that only the most integrated and individualized services should be developed, then the burden is on you to figure out what to do with all of the people in institutions or left unserved in the community. You can't just write these people off. This is what Jerry Provencal means when he refers to a "sense of urgency."

No service system has developed a large number of integrated and individualized community living arrangements in a short period of time. But this doesn't mean that it can't be done. No one has really tried. In fact, it is only in the past several years that people have started trying to find _homes_ in the community for people with severe disabilities. As places in Michigan, Nebraska, Kentucky, and elsewhere place more and more people with severe disabilities in homes in the community, we are slowly accumulating the experience to do this on a broader scale.

If, on the other hand, you are committed to getting people out of institutions into "better" places in the community, even if this means operating group homes, then, it seems, the burden is on you to show that you can move towards "good" services in the future. A couple things seem important. First of all, don't lock yourself into group homes. Don't buy facilities. Many states and agencies act as though they're in the real estate business. The more resources that are tied up in facilities, the harder it will be to move people out. This is one of the lessons of institutions. Second, develop some alternatives to group facilities, if only on a small scale. Find and support some families for children; develop some non-facility-based services for adults. In doing this, serve people with the most severe disabilities. In the long run, this will give you a base of practical experience and demonstrate that everyone can live in a home. Good models always drive out bad ones.

There are also some better or worse, more or less integrated, ways to operate group homes. Here are some suggestions.

1. Develop smaller facilities. If you have to develop group homes, make them smaller rather than larger. As we have argued, small size alone doesn't guarantee a high quality of life or high degree of integration. However, smaller settings are almost always more "home-like" and less "restrictive" than larger ones. Region V's "mini-group homes" for three or four people have a more "homey" atmos-

phere than any group home for five, six, or more people you could find. It is also easier to find three or four people who get along than five, six, seven, eight, ten, or twelve. Small size also encourages a greater level of individualization and makes it easier for the staff members to get to know each person as an individual.

2. Place people with a range of disabilities together. In other words, try "heterogeneous," rather than "homogeneous" groups. When selecting people to live at group facilities, don't put people with severe or profound mental retardation, autism, medical involvements, challenging behaviors, or multiple disabilities together. There are several reasons for this. The first relates to role modeling. When people with the same needs are grouped together, they are inclined to learn the wrong things from each other. The second is that staff members are less likely to feel "burned out" when they deal with people with a range of needs and abilities (as opposed to dealing with a number of people with, say, challenging behaviors). The final reason is that settings serving people with a range of needs are less likely to become "institutional." When you serve a number of people with medical involvements, multiple disabilities, or behavioral involvements together, care tends to get mechanical and daily life and routines become regimented.

3. Integrate people into the community. Just because people happen to live in a group facility this doesn't mean

that they have to be cut off from community life. We're not talking here about van rides to the sheltered workshop or day activity center or field trips to the circus or theatre. When we refer to integrating people into the community, we are talking about one, two, or perhaps three people going shopping, eating in restaurants, attending community activities, interacting with people as individuals rather than as members of a group, and beginning to develop meaningful relationships with other people in the community.

4. Teach people "functional" life skills. People with severe disabilities need opportunities to learn practical skills to participate as fully as possible in home and community life. This doesn't mean that people have to be "programmed" 24 hours-a-day, with all of their activities recorded and charted. It does mean that opportunities for people to learn life skills should not be lost. In any community setting, somebody has to cook, clean, grocery shop, and perform dozens of other daily tasks. People with severe disabilities should participate in these activities, if only partially (see Baumgart, et. al., 1982). It also means that staff members should focus on teaching people functional skills. In many group homes, the staff sets aside time for programming and activities anyway. They should use this time to teach people practical skills instead of duplicating prevocational center activities.

5. Avoid institutional trappings. This could be stated in a more positive way; namely, make the setting as

"normalized" as possible. The problem with saying this is that much of the true meaning of normalization has been lost. Indeed, Wolfensberger (1983) has abandoned the term for what he calls "social role valorization": placing people with disabilities in valued social roles. Not long ago, we visited a relatively small group home for young adult men. It was a small facility, with attractive furniture and numerous furnishings and amenities. The place was indeed "normalized" and "home-like". Each man's bedroom was decorated with "culturally age-appropriate" possessions. Staff members had obviously given a lot of thought to what young men have in their rooms. In the first bedroom, a perfectly appropriate poster of a football star hung on the wall. It was not until one saw the same poster in the second bedroom, the third bedroom, and the fourth bedroom that it became obvious that here normalization represented items on a checklist or rating instrument rather than a philosophy of how to serve people. The lesson of this is treat people as people, as unique individuals with their own needs and preferences. Avoid making institutions in the community. Some practices associated with institutions are creeping into community facilities: separate bathrooms for staff; kitchens and other rooms being off-limits to "residents"; mealtimes revolving around staff routines; separate meals for staff and "residents"; and others.

Finally, if you're operating or developing group homes, there seems to be some truth in the saying that compromises are more acceptable when one acknowledges them as such. For when you admit that you're making a compromise, you reduce your personal stake in what you have done and develop a sense of what you must do in the future.

CONCLUSION

Recently we were at a meeting when a discussion broke out about whether we, as a field, really know how to achieve community integration. On the one side stood people who argued that the know-how exists today to integrate people with the most severe disabilities into the community. On the other side were those who took the position there are no simple solutions to helping people with disabilities lead the good life in the community.

Do we know how to achieve community integration? We know that in many parts of the country - an increasing number - people with the most severe disabilities are living and thriving in the community. We know how to design funding mechanisms, recruit foster families, and implement quality safeguards. We know how to teach people with severe and profound retardation, design alternative communication systems for people who cannot speak, suction and position people with medical involvements, and develop nonaversive behavior programs for people with challenging behaviors. There are things we don't know. We don't know how to get complex service systems to always do what we think they should. We don't know how to translate ideas developed in fertile environments to ones not so open to innovation and change. We don't know what makes for the right chemistry in matching families or staff with people with severe disabilities.

We do know, however, that good people are doing good things for people with the most severe disabilities across the country.

They are committed to community integration and are providing answers to the things we don't know. They are making community integration work, not perfectly perhaps, but making it work nonetheless. This much we know.

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APPENDIX I

Resources, Ideas and Strategies for Developing Integrated Community Services

Appendix I

Resources, Ideas and Strategies for Developing Integrated Community Services

Are you interested in developing the integrated community services described in this manual? Do you need more information about where to begin? If so, this appendix can serve as a starting point.

In these pages, we share with you some practical ideas, strategies and resources for developing integrated community services for people with severe disabilities. The ideas and strategies are based primarily on the experience of people across the country who have or are developing these services. The resource materials are selected from an extensive review of the literature and from materials shared with us from different parts of the United States.

The areas addressed in this appendix reflect commonly asked questions about community service development. From the recruitment of foster parents to the funding of services to the development of job placements, we share with you a sampling of approaches and resources.

There are several points to keep in mind when using this appendix. First, the ideas presented here have come from a range of sources, including small and large agencies, parents and consumer groups, and regional and state service systems. Not every idea will apply to your particular role within the system (e.g., parent, funder, consumer, service provider, planner). Second, particular strategies need to be adapted to the dynamics and unique circumstances of your area. For example, each area has its own politics, economics and history that needs to be taken into account in developing strategies. Third, some of these practical ideas apply to the development of highly individualized services and others apply only to small settings (e.g., group homes or enclaves). For example, gaining community acceptance will not be as critical an issue as we develop more individual job placements and homes. Finally, this section is not designed to be read in its entirety. Simply turn to the questions that are of most interest to you.

We hope these ideas, strategies and resources will be a useful starting point for developing integrated community services for people with severe disabilities in your community. Use these ideas; add your own; build on them; share them with others. For more detailed information on developing community services, contact the Center on Human Policy, Community Integration Project, Syracuse University, 123 College Place, Syracuse, New York 13244-4130.

Assessing Community Needs

The literature is filled with systematic needs assessments and with ways a variety of groups can be effectively involved in assessing community needs. This section focuses on some ideas for bringing the "real lives" of people forward as part of the needs assessment process. The ideas center primarily around visible demonstrations of needs/service problems, processes of assessment that are also community "consciousness-raising" exercises, and consumers speaking for themselves.

How can I assess community need?

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* Develop, as a community, checklists of what to look for in terms of small, integrated community services.

* Find out how many people from your community live in institutions, nursing homes and private facilities and compare this to the number in group homes, foster care and other community living arrangements.

* Develop, as a community process, a checklist of integrated generic services available on the local level.

* Hold community hearings at which consumers, both served and unserved, can provide testimony on what has been most helpful or what is most needed.

* Contact local agencies to find out if they have waiting lists for service.

* Create on a local level, "symbolic demonstrations of need" (e.g., people could en masse, try to use various transportation services or public facilities as a way of demonstrating service inaccessibility).

* Conduct semi-structured interviews with parents and people with disabilities about their current experiences with services and their needs.

* Interview local rehabilitation service providers to find out how many people are in sheltered workshops compared to integrated work sites.

* Prepare descriptive reports of your visits to existing community settings.

Familiarizing Parents, Other Family Members and Friends with Community Services

Some families and friends may not be familiar with community services. Others may have only limited information about community options and may not know if community alternatives are "right" for their son, daughter, brother, sister or friend. This section gives some ideas on how families and friends can learn more about existing community services and what it can mean for the life of their family member or friend.

Service providers sometimes mention that a number of parents do not want their chid to move from an institutional to a community setting, from a sheltered workshop to an integrated job site. The ideas presented in this section respect the point of view of the parent and/or guardian and offer some suggestions for familiarizing them with community services.

How can I familiarize, parents, other family members and friends with community services?

---

* Involve parents and significant others in planning, developing, and evaluating services.
    - Actively involve all significant family members in planning for a move to the community from the beginning.
    - Have planning meetings at times when parents/guardians can attend.
    - Regularly ask parents for their input.
    - Involve parents on boards, advisory committees and monitoring groups.
* Use a variety of first-hand experiences to help parents/ guardians get to know community options.

  - Visit a community home or integrated work site with the parents or guardians.
  - Show parents the specific home where their child will live.
  - Have parents meet the people "in charge".

* Link a parent/guardian to another parent for support or advocacy.
  - Match a parent whose child is in an institution with a parent whose child lives in the community.
  - Refer a parent to an advocacy group or community agency that can give an unbiased opinion of the local community services.
  - Link a parent to a parents' support group.

* Hold community forums or training workshops on community services.
  - Provide stipends or keep costs low so parents can attend.
  - Hold at convenient times and/or a variety of times.

* Provide families with a "guide" (i.e., placement coordinator) who can visit and spend time with the family (e.g., on weekends at their homes.)

* Insure service quality and legal accountability of services and convey this information to parents/guardians.

* Obtain and read:
  - Perske, R. & Perske, M. (1981). Hope for the families: New directions for parents of persons with retardation or other disabilities. Nashville, TN: Abingdon Press.

Gaining Community Acceptance

One of the major problems in establishing community services, particularly residential options, is the gaining of community acceptance. Issues of zoning and neighborhood resistance remain central. As we move towards smaller, more integrated options, the potential for full community acceptance is increased. The ideas presented here represent some of the wealth of information which providers have on ways to gain community acceptance.

What are some ways that I can develop community acceptance?

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* Develop a community-minded board that has well-developed local ties (e.g., respected clergy, business people, lawyers, parents).

* Maintain ongoing relationships with your state legislators and other local elected officials during non-crisis times.

    - Familiarize them with people who are disabled and their families and with issues regarding community services.

* Become an active part of your neighborhood.

    - Take part in neighborhood social activities (e.g., church dances, local sports events).

    - Participate in the tenants' association or neighborhood watch group.

    - Hire neighborhood youth to cut grass and hedges.

    - Make use of area services (e.g., films, public library, churches)

    - Shop at neighborhood stores (e.g., groceries, department stores, barbers, hardware stores).

    - Invite neighbors over for coffee or a party.

* Do your "homework" for public hearings.

    - Have supporters there from the neighborhood (e.g., local clergy, business people, school personnel, parents).

  - Identify studies on property values that can be used to address the neighbor's concerns.
  - Know your people as individuals and their story.
  - Know the applicable regulations and laws.
  - Get to know the character of the local community.
  - Spend time talking with neighbors as individuals.

* Be conscious of the appearance of your homes.
  - Maintain the lawn well in summer and keep sidewalks clear of snow in winter.
  - Plant flowers and shrubs.
  - Upgrade the exterior of the house (e.g., buy a new awning, do touch up painting).

* Organize a rally of parents, consumers, and human service workers to support community living.

* Develop allies with the local police, emergency personnel and management; help them to know your people and your services.

* Have neighborhood advisory boards or program advisory committees that have representatives from the neighborhood.

* Develop small individualized options versus large group homes or work sites; disperse residential and vocational options throughout the community.

* Use a "bidding approach" in selecting small rural towns as work sites (i.e., indicate to the town what is needed including types of work, zoning changes, relationships with medical, industrial and religious organizations; see what they can offer before selection).

* Promote the dignity of people with disabilities.
  - Use respectful language language.
  - Dress nicely.
  - Avoid accepting "charity" on behalf of persons with disability.
  - Promote real work and real contributions to neighborhood life.

* Hire staff who know and/or are from the geographical area to be served.

* Obtain and read:

- Bates, Marion. (August 1985). State Zoning Legislation. Wisconsin: Wisconsin Developmental Disabilities Council.
- Nelson, Roberta. (1978). Creating Community Acceptance of Handicapped People. Springfield, Illinois: Charles Thomas Publishing.
- Perske, R. (1980). New life in the Neighborhood: How Persons with Retardation and Other Disabilities Can Help Make a Good Community Better. Nashville TN: Abingdon Press.
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Recruiting Foster Parents

In this manual, we stressed the importance of children living with families. In situations where the natural family can no longer care for their child, a foster family for the child may need to be found. Providers, who are committed to the need for children to live with a family, have discovered ways of matching children with severe disabilities with caring families. Some providers recruit large numbers of potential families and then screen the families to find the right match. Others start with the needs of the person with a disability and look for a family that is "just right" for the child. Although the methods may vary, two beliefs are common to both approaches. First, families are not interchangeable; and second, "matches" for children with severe disabilities can be found.

How can I recruit foster parents?

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* Use a wide variety of recruitment techniques:

- news releases
- public service announcements
- bumper stickers
- brochures
- posters
- bulletin board notices
- feature articles
- referrals from other foster parents
- classified ads
- films
- special handouts/flyers
- sound/slide show
- information booklets
- shopping mall displays
- TV interview shows
- whatever else you can think of

* Send a letter about the program to community services groups including:

- social service agencies
- adoption agencies
- employment agencies
- college placement offices
- women's centers
- college counseling offices

  - school districts
  - college instructors
  - church organizations
  - professional organizations
  - social clubs

* Contact hospitals in the area and ask for their assistance in publicizing information to employees.

* Develop a letter and flier to send to nurses for severely medically involved children.

* Schedule presentations through college placement offices, instructors and department heads.

* Offer a variety of supports to foster families.

  - person to call anytime day or night for support
  - respite
  - professional consultations such as nurses and occupational therapists
  - home aides
  - financial assistance for special equipment, supplies, home modifications
  - individual parent-to-parent support linkages
  - parent support groups

* Involve families in the recruitment process.

  - Have families "share their story" to a variety of other audiences (including families).

  - Match a recruited family with another potential family to listen and share understandings.

  - Encourage visits between the potential foster family and person with a disability to insure a good match.

* Try a variety of foster care models.

  - Build on the foster model if needed by providing a budget to hire staff to supplement family members.

  - Develop the option of shared care between foster and natural families (i.e., an arrangement where natural and foster parents agree to share responsibility for raising the child).

  - Develop permanent foster care agreements (i.e., nonlegal agreements by foster families to serve as primary parents for children until adulthood).

* Obtain and read:

  - Macomb-Oakland Regional Center. Community training home informational booklet. Macomb-Oakland Regional Center, 16200 Nineteen Mile Road Mt. Clemens, MI 48044.

Supporting Families

There is an increasing awareness in this country of the importance of supporting families in the care of their child with a disability. As of July 1985, at least twenty-four states had some type of family support/home care program.

Family support services refers to a variety of supports or resources that can enable the person with a developmental disability to remain in their home with their famiy. The type of supports varies, but may include cash subsidies, respite, counseling, specialized equipment, architectural modifications of the home, transportation for the person with a disability, homemaker services, chore services, diagnostic and recreational services. Family supports need to be made available to natural, adoptive, foster families.

How can I support families?

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* Involve families in the design and evaluation of family supports, preferably on a local level.

* Look at the needs of the entire versus not just the needs of the one member with a disability.

* Individually, design with a family the array of supports that is "right" for them.

    - Familiarize families with existing services and options.

    - Allow for flexibility in the types of services provided (e.g., purchase of washcloths may be essential to obtaining other services).

    - Help the family to identify the critical supports for them.

* Build on a family's existing community supports versus supplanting these supports.

- Use recreational opportunities in community agencies as a form of natural respite for families.

- Involve neighbors and friends in providing respite.

- Have families play a role in recruiting and training their respite workers.

* Offer a variety of supports to families

  - person to call anytime day or night for support
  - respite
  - individual parent-to-parent support linkages
  - parent support groups
  - financial assistance for special equipment, supplies, home modifications
  - support gropus or linkages for brothers and sisters
  - home aides
  - respite
  - professional consultations such as nurses and occupational therapists
  - other supports determined by the family

* Develop mechanisms that maximize consumer control and choice.

  - Use a voucher system for purchasing services from a "menu" of services (e.g., foster home respite, home-based respite care, family/friend respite care, drop-in day care).

  - Pilot a cash subsidy program to help parents pay for the extra expenses incurred.

* Obtain and read:

  - Bates, M. V. (1985). State family support/cost subsidy programs. Madison, Wisconsin Council on Developmental Disabilities, 1 West Wilson Street, P.O. Box 7851, Madison, Wisconsin 53707.

  - Cohen, S., & Warren, R.D. (1984). Respite care: Supporting families of developmentally disabled persons. Austin, TX: Pro ED.

  - Frisbie, D. and Slater, K. (Eds.). (1979). Family Support Project: Final report for the period of January 1, 1979 through September 30, 1979. ERIC document 219 919.

  - Tingey-Michaelis, C. (1983). Handicapped infants and children: A handbook for parents and professionals. Austin, TX: Pro ED.

Training and Supporting Staff in the Community

Training staff to work with persons with severe disabilities in community settings requires an increased focus on (1) strategies for community integration, (2) functional programming (i.e., if you cannot do something for yourself, someone will have to do it for you), and (3) specialized training (e.g., medical, behavioral) geared to the needs of specific individuals. Staff training needs to emphasize both philosophical principles and technical skills (e.g., meal planning, task analysis, non-handicapped person inventories, managing a budget, first aid).

Ongoing support and development of staff is an important goal from both an administrative and a consumer perspective. Staff growth and development not only builds "program expertise," but also increases staff retention and provides valuable role models to persons with disabilities.

How can I train and support staff in the community?

- Have a new staff member follow a more experienced staff member as they work in the community.
- Gear specialized training (e.g., physical therapy, seizures, non-aversive behavioral techniques) to needs of the specific individuals being served.
- Develop contracts or memos of understanding with medical and behavioral consultants to train staff to work with specific individuals. Have consultants observe during evenings and weekends in homes and develop programs in conjunction with staff.
- Involve staff, parents and consumers in planning, implementing and evaluating all staff training activities.
  - Have parents train their respite provider on the specific needs of their child.

  - Have direct service staff lead issue - oriented discussion sessions.

- * Provide opportunities for staff linkages and support.
  - Use a portion of staff meeting time for problem solving, issue-oriented discussions.
  - Hold "staff days" or social times for staff to get to know each other.
  - Link staff members with each other for phone-to-phone support on specific issues.

- * Hold community or regional forums on current service issues (e.g., use consultants and outside experts to inspire).

- * Have staff spend a week working with specific individuals at the institution before people move to their new home(s).

- * Develop administrative practices that support staff development.
  - Include peer feedback and self-evaluation as part of the personnel evaluation process.
  - Revise job descriptions to focus on staff's role in facilitating community integration.
  - Maintain staff training coordination as a rotating function versus isolating it in a department or role.

- * Use existing training resources.
  - Form a training coalition with other agencies to maximize resource availability (e.g., video equipment, books, speakers).
  - Use generic resources in the community (e.g., Cooperative Extension for household issues, Fire Department for fire safety issues).
  - Contact a University Affiliated Facility or Research and Training Center for information on available training materials.

- * Develop a core team of professionals (e.g., nurse, behavioral specialist etc.) that can consult with contract agencies regarding specific individuals.

- * Provide adequate funding for staff that includes time for staff training and development.

* Obtain and read:

- McCarthy, T. (Ed.) (1980). *Managing group homes: A training manual*. Nashville, TN: TMAC Behavior Development, Cost: $14.95.
- Provencal, G. & Evans, D. (1977). *Resident manager education: A curriculum model for educating foster parents and group home personnel*. Macomb-Oakland Regional Center, 16200 Nineteen Mile Road, Mt. Clemens, MI.

Retaining Good Staff

Retaining good staff is important for the continuity of relationships as well as for fiscal and management considerations. One of the most common threads in our interviews of "model programs" was the importance of letting staff know they are valued. Common themes included respecting staff, involving staff in decision-making, instilling "ownership," trusting staff decisions, giving staff responsibility and providing staff with needed supports. A number of people also mentioned the importance of job variety, including working with a heterogeneous group of people, as a factor in maintaining good staff morale.

How can I retain good staff?

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* Try job sharing among staff in different roles.
    - Rotate the program coordination function (including on-call) amongst the house directors on a weekly rotation.
    - Have administrators spend part of their time on a regular, planned basis in a direct service role.
    - Have each staff member involved in clerical, training, program and administrative functions (including job placement).
* Provide direct service staff with responsive back up supports at times needed (e.g., evenings, weekends) and in a personal manner (e.g., phone, in person).
* Regularly feature articles on staff members, their accomplishments and their innovative ideas in newsletters.
* Encourage staff to publish articles and make regional and national presentations.
* Clearly define staff roles and trust staff to make decisions within those roles.
* Develop an employees' advisory committee.

* Encourage staff to give feedback on needed changes both through informal and formal processes (e.g., surveys, suggestions boxes, "open door" policy).

* Offer an employee of the month award and a house of the month award (e.g., traveling plaque, day off with pay).

* Develop merit pay systems and incentives.

* Involve staff at all levels in decision-making.

    - Solicit staff input in planning (e.g., designing of personnel evaluation tool).

    - Give direct service staff flexibility to adjust service plans.

    - Allow supervisors to screen and hire their own staff.

    - Include staff in evaluation and systems review processes.

    - Develop with staff a common vision of services.

    - Include a staff representative on boards and/or planning committees.

* Develop regular opportunities for sharing and problem solving amongst teams and across teams.

* Foster peer group support amongst staff (e.g., pot lunches, visits to other services) and staff-to-staff support linkages.

* Use heterogeneous groupings; do not cluster "high need" residents.

* Provide staff development opportunities (see Developing Staff Training).

Developing Integrated Work Sites

As we move away from sheltered workshops to integrated work, we need to develop strategies to locate a variety of integrated community work sites. "Work sites" in this section refer to both sites where people with disabilities are paid for their work and sites where initially no compensation is received. The level of integration at the site may also vary depending on size, nature of the work, kind of position and specific location of the job(s).

How can I develop integrated work sites?

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* Provide information to employers on available tax incentives.
* Develop a board or advisory group with strong connections with business, industry and community organizations.
* Describe ways in which the work station, job crew, or integrated option can benefit the employer (e.g., reduce problems related to staff turnover, provide positive publicity).
* Use existing work sites as "references" for further development of other options.
* Use business marketing techniques(e.g., brochures, slide shows).
* Look beyond traditional janitorial or service sites to positions in a variety of other settings (e.g., sites in medical facilities, in sports facilities).
* Develop work study placements in integrated settings during the school years that can become work sites during later years.
* Survey parents to identify those who own or manage their own businesses.
* Have staff list the places where they do business (e.g., gas stations, grocery stores).
* Match the individual characteristics of the potential employee with the conditions and requirements of a particular job site.

* Know your local industries/companies and their needs for employees and match your marketing approach to their needs.

* Look at job opportunities in a person's own home neighborhood; use contacts already familiar to the family or friends.

* Find a work situation that fits or can be modified to fit the individual (e.g., for a more medically fragile individual, consider a work site in a hospital).

* Retain staff highly skilled in job analyses, task analyses, partial participation, integration strategies and non-aversive behavioral intervention techniques as well as in business techniques/strategies.

* Provide assurances to the employer (e.g. continued follow-up and on-call support to the employer, adequate staff support to both the person with a disability and to co-workers, back up personnel as needed).

* Talk with the potential employer about a specific person who could be employed in their business.

* As you go about your day, keep an "eye out" for potential job sites; ask your friends to do the same.

* In particular, identify small to medium size businesses as potential job sites.

* Show an interest in the employer's business; convey to coworkers the value of their jobs.

* Conduct ecological inventories (i.e., written, step-by-step observations of any activity, as performed by a nondisabled person who typically does the activity).

* Conduct a discrepancy analysis (i.e., an onsite evaluation of the worker that determines actual performance in comparison to the skills identified in the ecological inventory).

* Modify a job already being performed or develop a job which combines required skills (e.g., combine the filing responsibilities of six secretaries into a new position).

* Use adaptive devices when needed (e.g. metal flap for folding letters office filers).

* Provide the employer with the information and support necessary to perform a portion of the job training.

* Have the public school prepare an individual to function in a specific work site subsequent to graduation with transfer of the responsibility for maintaining the placement shifting to the adult service agency upon graduation.

* Locate job environments which maximize interactions and relationships with nondisabled persons.

* Obtain and read:

  - Albright, L., Hasazi, S.E., Phelps, L.A., & Hull, M. (1981). Interagency collaboration in providing vocational education for handicapped individuals. *Exceptional Children*, 47, pp. 584-589.

  - Bellamy, G.T., Rhodes, L.E., Wilcox, B., Albin, J.M., Mank, D.M., Boles, S.M., Horner, R.H. (1984). Quality and equality in employment services for adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, *9* (4), 270-277.

  - Bellamy, G.T., Sheehan, M.R., Horner, R.H., & Boles, S.M. (1980). Community programs for severely handicapped adults: An analysis. *Journal of the Association for the Severely Handicapped*, 5 (4), pp. 307-324.

  - Brown, L., Shiraga, B., York, J., Kessler, K., Strohm, B., Rogan, P., Sweet, M., Zanella, K., Van Deventer, P., & Loomis, R. (1984). Integrated work opportunities for adults with severe handicaps: The extended training option. *Journal of the Association for Persons with Severe Handicaps*, *9* (4), 262-269.

  - Nietupski, J. A., Hamre-Nietupski, S., Welch, J., & Anderson, R. J. (1983). Establishing and maintaining vocational trainers. *Education and Training of the Mentally Retarded*, *18*, pp. 169-175.

  - Wehman, Paul (1981). *Competitive employment: New horizons for severely disabled individuals*. Baltimore: Brookes.

Developing Individualized Placements

This manual stressed the importance of moving away from facility-based service models to more individually-tailored placements. A common misunderstanding is that an individualized placement means the person will live or work alone. This will not always be the case. In some circumstances, an individualized placement may mean that two people, both of whom are disabled, decide to live together. Or that several people with disabilities work at the same site. A facility-based model starts with the places first (e.g., a group home) and the person then is matched with the "best" available place. An individualualized placement starts with the person first and the type and amount of supports needed are then built around the individual.

How can I develop truly individualized placements?

- Design a system of support services around the individual person's needs and preferences.
- Provide assistance, advice, support or advocacy in the areas important to the person.
  - Help in finding and selecting housing and roommates.
  - Help in arranging live-in support.
  - Training in learning to manage money, take care of one's health, plan and prepare meals, shop and take care of one's own home.
  - Assistance in solving problems and making decisions.
  - Help in furnishing, moving and decorating a new home or place.
  - Help in obtaining other services and in using community resources.

  - Help in developing meaningful relationships and leisure pursuits.

  - Provision of whatever combination of supports that the person needs and wants.

* Adjust support services as the person's needs change instead of having the person move.

  - Fade supports over time.

  - Provide additional supports when needed during crisis or change.

* Provide supports for as long as they are needed for the person to successfully live in a home of his/her own in the community or to continue in his/her job.

* Design a consumer-directed service (e.g., help the person identify his/her needs and preferences and help them organize ways to meet those needs).

* Assist people to rent and/or own their own homes.

* Teach community skills in the community instead of "preparing for" the community.

  - Have people with severe disabilities participate in daily activities to the extent possible (i.e., partial participation).

  - Adapt teaching strategies used effectively in schools with severely disabled students for use in community homes and jobs; blend the teaching into the day-to-day routine.

* Make support services available wherever the person lives or works.

* Make adaptations to the environment.

  - "voice" telephone for a person who cannot dial the phone

  - automatic door openers and lockers for people who cannot use regular handles and locks

  - stoves and countertops accessible if a person uses a wheelchair.

* Build on natural supports.

  - Help people to get to know their neighbors.

  - Have coworkers and employers play part of the training role.

- Assist people in getting to know friends.

* Obtain and read:

- Baumgart, D., Brown, L., Pumpian, I., Nisbet, J., Ford, A., Sweet, M., Messina, R., & Schroeder, J. (1982). Principle of partial participation and individualized adaptations in education programs for severely handicapped students. *Journal or the Association for Persons with Severe Handicaps*, *7* (2), pp. 17-27.

- Bellamy, G.T., Stern, A.J., Newton, S., Roma, M., Boles, S.M., Horner, R.H., & Tends, T. (1984). *Neighborhood living project: Intensive tenant support model*. Eugene, OR: Center on Human Development, College of Education, University of Oregon.

- Board, M.A., Cole, J. A., Frieden, L., & Sperry, J.C. (1980). *Independent living with attendent care: A guide for the person with a disability*, *A guide for the personal care attendant*, *A message to parents of handicapped youth*. Houston, TX: The Institute for Rehabilitation & Research.

- Brown, L., Branston, M.B., Hamre-Nietupski, S., Pumpian, I., Certo, N., & Gruenewald, L. (1979). A strategy for developing chronological age appropriate and functional curricular content for severely handicapped adolescents and young adults. *Journal of Special Education, 13 (1)*, pp. 81-90.

- Ford, A., Brown, L., Pumpian, I., Baumgart, D., Nisbet, J., Schroeder, J. & Loomis, R. (1984). Strategies of developing individualized recreational/leisure programs for severely handicapped students. In N. Certo, N. Haring, & R. York (Eds.). *Public school integration of the severely handicapped: Rational issues and progressive alternatives*. Baltimore: Paul Brookes. (pp. 245-275).

- Ford, A., & Mirenda, P. (1984). Community instruction: A natural cues and correction decision model. *Journal of the Association for Persons with Severe Handicaps*, *9* (2), pp. 79-88.

- Johnson, Terri Z. (October, 1985). *Belonging to the Community*. Wisconsin Options in Community Living and the Wisconsin Council on Developmental Disabilities.

- Perske, R., Clifton, A., McLean, B. M., & Stein, J. I. (Eds.). (in press). *Mealtimes for severely and profoundly handicapped persons: New concepts and attitudes* (revised edition). Baltimore: Brookes.

- Vogelsberg, R.T., Anderson, J., Berger, P., Haselden, T.L., Mitwell, S., Schmidt, C., Skowron, A., Ulett, D., & Wilcox, B. (1980). *Selecting, setting up, and surviving in an independent living situations: An inventory and instructional approach for handicapped individuals*. Burlington, VT: Center for Developmental Disabilities.

Obtaining Community Services

Full participation of persons with severe disabilities in community life requires access to the diverse range of services provided by community agencies. A three-pronged focus, including community education, specific efforts with these agencies, and support and training of persons with disabilities are represented in the following ideas and practices.

How can I obtain community services?

- In small rural communities, join with the community members to bring in needed specialists to the area (e.g., occupational therapists, anesthesiologists, physical therapists).
- Provide on-site consultation and support to local agencies on integration.
- Offer to provide training to their staff, if desired, consultation on specific issues and orientation to group members.
- Use neighborhood recreational facilities, stores, laundromats, coffee shops and churches both individually and in small groups.
- Help your community to apply for funds for accessibility modifications and to conduct consumer-led accessibility surveys.
- Start a service that matches non-handicapped volunteers and persons with a disability on the basis of leisure preferences.
- Develop resource lists of physicians, dieticians, and therapists who are particularly receptive to working with persons with developmental disabilities.
- Provide training to ambulance and emergency room personnel on your services and the needs of your people.
- Sponsor physician-led training of other physicians on developmental disabilities using existing curricula.
- Talk with your local restaurant columnist about including a notation on accessibility for each restaurant reviewed.

* Involve a range of community members on boards and planning groups (e.g., doctors, nurses, lawyers, business personnel) and have them get to know the individuals you serve.

* Use available technology to assist persons with disabilities to participate fully in community activities (e.g., non-handicapped person inventories, non-aversive behavioral techniques, task analysis, etc.)

* Assist generic agencies to obtain positive publicity for their efforts.

* Approach local community groups, together with the generic agencies, for funding for adaptive equipment.

Serving People with Extensive Medical Needs in the Community

Some people labelled as "medically fragile" are living with families and in small group homes in different parts of the country. As with other people, children and adults with extensive medical needs also have the same basic needs as all of us (e.g., the need to be loved, and the need for a home).

The types of additional supports that will be needed for a person with extensive medical needs to live in the community will vary from person to person. The additional supports needed are usually not complex, but may involve consultation by medical personnel, the availability of specialized equipment, and the availability of accessible support services.

How can I serve people with extensive medical needs in the community?

---

* Make use of local pediatricians and doctors.

* Locate homes in close proximity to a hospital.

* Have available in the home any specialized equipment needed for the individual (e.g., suction machines, oxygen, vaporizer).

* Inform the local ambulance service about any particular needs of people with extensive medical involvements.

* Have access to a 24 hour nurse (on-call and/or on-site).

* Recruit foster parents and staff who have some knowledge and comfort with health-related needs.

* Make use of clinical consultants.

- Arrange to use private clinical consultants (e.g., occupational, physical or speech therapists, nurses, dieticians).

- Have consultants monitor service delivery and act as role models.

- Have consultants train staff in the medical needs of specific person.

* Select a job site based on the needs of the person (e.g., a hospital as a site for a person with periodic medical needs).

* In small, rural communities, join with the community to bring in needed specialists (e.g. anaesthesiologist).

* Obtain and read:

  - Finnie, N. R. (1975). Handling the Young Cerebral Palsied Child at Home (Second Edition). New York: Dutton-Sunrise.

  - Jones, M. L. (1985). Home Care for the chronically ill or disabled child: A manual and sourcebook for parents and professionals. New York: Harper & Row.

  - Fraser, B.A., & Hensigner, R.N. (1983). Managing physical handicaps: A practical guide for parents, care providers, and educators. Baltimore, MD: Brookes.

  - Dixon, G.L., & Enders, A. (1984). Low cost approaches to technology and disability. Washington, DC: National Rehabilitation Information Center, Catholic University of America.

Serving People with Challenging Behaviors in Integrated Community Settings

People with "challenging behaviors" are increasingly being served in the community in different parts of the country. The practices that characterize good programs and services for people with disabilities also apply to services for people with "challenging behaviors." Thus, the ideas contained under other headings (e.g., functional programming, staff training and support) also can be listed under this section.

The additional supports that people with "challenging behaviors" needs will vary from person to person as will the type of support that the families and/or staff will need. The availability of accessible and flexible supports, however, does appear to be key. In some situations, ongoing consultation from a person skilled in working with people with "challenging behaviors" will also be needed.

How can I serve people with challenging behaviors in integrated community settings?

---

* Use "positive programming" strategies with people with challenging behaviors.
    - Teach the person another alternate response to the situation (e.g., use a punching bag when angry).
    - Teach the person an alternate way to communicate their needs or feelings (e.g., "I am angry. Go away.")
    - Modify the program through the use of ecological, curricular or instructional strategies (e.g., greater involvement in active pursuits.)
* Look particularly toward more individually - tailored options for people with "challenging behaviors".

- Choose a job site where the particular "behavior" is not an issue.

- Build a support group around the individual (e.g., advocates, friends).

- For group living arrangements:

  - Keep the size of the group as small as possible. (e.g. two or three people)

  - Do not group people with challenging behaviors in the same setting.

  - Insure the availability of adequate private space within the home.

- Provide support and training to staff and families through the use of behavioral consultants.

  - Have consultants available during evenings and weekends.

  - Develop contracts with behavioral consultants to train staff and families to work with specific individuals.

  - Involve direct service staff and families in the design as well as implementation and review of any "behavioral" plans.

  - Have consultants monitor service delivery, act as role models, and work with staff and families to develop and assess programs.

- Select staff and foster families who want to work with the person with "challenging behaviors" (e.g., a person who views the individual as "spirited").

- Provide a range of supports to staff and foster families

  - funds to bring in additional support staff during particularly difficult periods

  - respite

  - persons to call anytime day, night or evenings for support

- Help the family and staff to look at the meaning of the behavior and its context within a person's life.

- Obtain and read:

  - McGee, J. J., Menolascino, F. J., and Menousek, P.E. (In press). Gentle Teaching. Austin TX: Pro Ed.

- Donnellan, A.M., Mirenda, P.L., Mesaroa, R.A., & Fassbender, L. L. (1984). Analyzing the communicative functions of aberrant behavior. *Journal of the Association for Persons with Severe Handicaps*, *9* (3), pp. 201-212

- Evans, I.M., and Meyer, L.H. (1985). *An educative approach to behavior problems: A practical decision model for interventions with severely handicapped learners*. Baltimore: Paul Brookes.

Funding Integrated Community Services

A variety of different funding sources have been used effectively to develop services that center on the individual instead of the program. The Medicaid home and community - based services waiver, together with a mix of local, state, and private funds, remains a primary funding alternative. A key issue in funding individualized services is to design administrative processes to keep the control of how the dollars are spent as close to the individual as possible.

How can I fund community services?

---

* "Mix and match" funding streams when feasible and in the best interests of the individuals.
  - Fund a small community living arrangement for mutually compatible roommates who are eligible for different funding (e.g., Medicaid Waiver and state funds.)
* Investigate the use of the Medicaid home and community - based service waiver to develop more individualized community options.
* If only funds for intermediate care facilities are available, consider the use of the funds to develop small (4 - 6 person) community living arrangements.
* To the extent feasible, access individualized needs-based funding on the local (county) level.
  - provide additional short term funding (1 - 6 months) for persons with particularly challenging needs.
* Conduct private fundraising to insure that individual service requests (e.g., for augmentative communication devices) can be met.
* Correct disincentives for the development of community-based services.
  - In states where there is a state - local share for community services there should be the same matching formula for state institutions.

- Revamp state developmental disabilities grant funding processes to encourage funding and "ownership" by the total local community.
    - Use a five year cycle where the state share decreases each year and is replaced by local non-governmental funding (e.g., private businesses, industry, church groups etc.)
- Locate private investors to purchase houses versus building or buying own facilities.
- Develop a private, non-profit agency to administer state family support services; use a developmental disabilities grant to hire a fund-raising consultant and identify board members.
- Use purchase of service options and cash subsidies to maintain consumer control and choice.
    - Pilot a cash subsidy program to help parents of children with disabilities to pay for the extra expenses incurred (e.g., equipment, respite, home renovations, diapers, other services, etc.)
    - Provide consumers with funds to hire their own personal care attendants.
    - Use a voucher system for purchasing respite services from a "menu" of service (e.g., foster home respite, home-based respite care, family/friend respite care, - drop -in day care).
- Adjust per diem funding for the individual; provide a range of per diems dependent on needs.
- Provide economic incentives to adoptive parents of difficult - to - place children.
- Encourage private health insurers to underwrite coverage for home health care.
- Expand the services provided under vocational training and consultation funding to include actual placement of persons with disabilities in jobs.
- Establish systematic procedures for businesses to contribute money to existing family support services.
- Provide case managers with a block of money to fund individualized service plans.
- Give foster care or extended families funds to hire additional support staff.

* As an interim step, adapt current rate-setting systems to better meet individual needs.

  - Allow for time-limited one-to-one services in excess of regular staff support when documented in the individual service plan.

  - Build in flexibility through the use of negotiated budgets.

  - Allocate block funding to regions with service and funding decisions made on a regional versus state basis.

* Build in supports to existing community services (e.g,. YMCA, YWCA) versus starting a new service for people with disabilities.

* Make use of existing mechanisms such as the targeted jobs tax credit and vocational rehabilitation job coaches to support new options.

* Obtain and read:

  - Gettings, R. M. & Salmon, S. (1985). Federal administration constraints on state medicaid outlays for mentally retarded and other developmentally disabled recipients: A state-by-state survey report. Alexandria, VA: National Association of State Mental Retardation Directors.

  - Copeland, W. C. & Iversen, I.A. (1985). Developing financial incentives for placement in the least restricitve alternative. In Lakin, K. C. & Bruininks, R. H. (Eds.) Strategies for achieving community integration for developmentally disabled citizens. Baltimore: Brookes.

  - Conley, R. W. (1985). Impact of Federal programs on the employment of mentally retarded people. In Lakin, K. C. & Bruininks, R. H. (Eds.) Strategies for achieving community integration for developmentally disabled citizens. Baltimore: Brookes.

Insuring Quality Services

The question of insuring quality services is a particularly critical one for a widely dispersed system of small, more individualized services. From integrated job placements to specialized foster care to in-home respite to supportive living, a variety of methods are necessary to insure continued service quality.

The ideas and practices described in this section involve a wide range of actors (e.g., parents, consumers, direct services staff, advocates, volunteers, professional) and a wide range of techniques. At a minimum, a mix of external and internal safeguards together with input from a variety of actors is essential to insuring quality services.

How can I insure service quality?

---

* Develop and fund a community monitoring group consisting of parents, consumers and interested citizens to look at quality of life issues in existing community homes.

* Develop "cluster groups" (e.g., residential, rehabilitation) consisting of area service providers, parents, consumers and interested citizens to review proposed services in-depth and to promote sharing amongst providers.

* Develop a regular comprehensive systems review process that focuses on people and programs as well as paperwork, that includes feedback from staff, consumers and parents, and that is both summative and formative in nature.

* Develop a Program Ethics Committee to review all research proposals and programs that might potentially restrict client rights, and to investigate instances of abuse and neglect; include all external people on the committee (e.g., parents, consumers, community members, attorneys, university specialists).

* Develop a Client Advisory Board that consists of representatives from all area agencies and reports directly to a regional management team.

- Implement a regular process of external review other than professional peer reviews and audits for compliance (e.g., citizen evaluation using Program Analysis of Service Systems).

- Actively encourage the development of self-advocacy efforts, including funding for independent advisors.

- Develop a range of internal mechanisms for maintaining quality.

  - written grievance procedures for staff and consumers

  - regular review of paperwork, record-keeping and safety/health standards.

  - annual consumer surveys

  - unannounced peer reviews within agency

  - annual establishment and review of goals and objectives by each department/team

  - quality circles involving voluntary employee participation in decision-making and problem-solving

  - clear philosophically-based mission statement.

- Encourage and support the involvement of parents and consumers on agency boards. Encourage board members to visit and spend time in homes/vocational sites.

- Implement a centralized case management system that is separate from direct service provision; have unannounced visits to homes during evening and weekend times.

- Encourage the input of neighbors; develop neighborhood advisory boards; foster the development of relationships between disabled and non-disabled people.

- Establish a semi-autonomous or autonomous agency to monitor service quality in the community-based programs.

- Conduct follow-up interviews or questionnaires on a random sample of "consumers" to track their satisfaction; use case-workers, students, board members and volunteers.

- Use a self-evaluation manual; develop a work group comprised of representatives from all levels of an organization (i.e., board of directors, agency administrators and staff) and from outside the organization (i.e., parents, consumers, interested citizens) to adapt the methodology to your own place.

- Use a private evaluation service consultant to assist in designing a quality assurance system.

* Obtain and read:

- Apolloni, T., Meucci, S., & Triest, G. (1981) Monitoring the quality of life experienced in living arrangements: A guide to citizen participation. California State Council on Developmental Disabilities, 1507 21st Street, Suite 320, Sacramento, CA 95816.

- Bersani, H.A. (1984). Monitoring community residences: Guidelines & Handbook. Columbus, OH: A R C - Ohio.

- Bradley, V.J. (1984). Assessing and enhancing the quality of services: A guide for the human service field. Boston, MA: Human Service Research Institute.

- Gardner, J. F., Long, L., Nichols, R., & Iagulli, D. M. (Eds.) (1980) Program Issues in Developmental Disabilities: A Resource Manual for Surveyors and Reviewers. Baltimore, MD: Brookes.

- Taylor, Steven J. (1980). A Guide to Monitoring Residential Settings. Syracuse, NY: Human Policy Press.

- Williams, P. & Shoultz, B. (1984). We can speak for ourselves: Self-advocacy by mentally handicapped people. Bloomington, IN: Indiana University Press.

Disseminating Information

A tremendous amount of information and knowledge is available throughout the country on developing integrated community services. It is critical that existing information be shared not only between planners and administrators on the state levels, but also with local communities.

How can I disseminate information on community services?

---

* Contact the Center on Human Policy for more information on integrated community services for people with severe disabilities.

* Use the local media to share stories on community life.

    - Feature stories in local newspapers on friendships between disabled and non-disabled people, on a new job site, on the meaning of respite for a family.

    - Use editorials, question and answer columns to increase community awareness and to share consumer and parental viewpoints.

    - Participate in local television "talk shows".

    - Make use of a variety of events (e.g., visitor from another state, new grant) as opportunities to publicize your services.

* Start a direction service in your area for information and referral and case follow along.

* Use existing computer technology to maximize information exchange on both local and state levels.

    - Maintain lists of persons that could assist families (e.g., qualified respite providers, building contractors experienced in removing home barriers).

    - Maintain lists of special equipment for sharing or exchange.

    - Maintain lists of useful publications and unpublished materials by topical area at regional centers.

- Use a variety of newsletters to disseminate information on training materials and state-of-the-art practices.

- Sponsor regional or local community forums with extensive media coverage.

- Encourage service providers to write about their experiences in developing services and about the effect on the lives of people with disabilities.

- Encourage and assist consumers to write about their experiences in both institutions and in the community.

- Obtain and read:

  - Davidson, Philip W., Reif, Michael E., Shapiro, Donald, Griffith, Bretna, Shapiro, Priscilla and Crocker, Allen C. (1984). "Direction Services: A model of facilitating secondary prevention of developmental handicapping conditions." Mental Retardation, Vol 22., No. 1, 22-27.

APPENDIX II

Programs Demonstrating Model Practices for Integrating People with Severe Disabilities into the Community

APPENDIX II

Programs Demonstrating Model Practices for Integrating People with Severe Disabilities into the Community

During the spring and summer of 1985 we conducted a national search for model programs which strive to integrate people with severe and profound mental retardation, autism, multiple disabilities, challenging behaviors, and medical involvements into their natural communities. Programs were nominated by the Community Integration Project's advisory panel of national experts on community services, project staff members, and by responses to a call for nominations which appeared in a variety of national newsletters including those published by the Association for Persons with Severe Handicaps and the United Cerebral Palsy Association. As a result of this process 65 nominations have been received to date.

Each nominated program was contacted by phone and an appointment made with a senior staff person for a formal phone interview. Each interview was conducted by a member of the project staff using a guide which covered background information, setting and program description, types of services provided, populations served, degree of actual community integration, staffing patterns, related services, administrative structures, parent and consumer involvement, cost, and funding mechanisms. This information was, in many instances, supplemented by a variety of materials provided by the respondents.

In addition to the phone interviews, 5 sites were selected for visits of from 1 to 2 days duration by project staff members. These sites were selected on the basis of multiple nominations which were unanimous in their high recommedations of the program. Also, with one exception, the sites selected for visits were regional service systems rather than individual agencies or programs. In these cases it would have been particularly difficult to gain a global understanding of how these services operated solely on the basis of a one hour phone interview.

Subsequent to the interviews and the visits the project staff reviewed the material collected and screened each program for basic conformity with the principles of community integration outlined at the beginning of this manual. As a result of this screening process 34 programs were included in this listing of model programs. (It should also be noted that at this time 12 programs are still in the process of being reviewed and additional nominations are still being received.)

A further analysis of these remaining programs was then carried out to elucidate any common threads which might be designated as hallmarks of integrated programs or "most promising practices" in the field of community-based services. This analysis provided the basis for the approach to services outlined in the body of this manual.

It was illuminating that many of these "model" programs did not see themselves as models. For all the good things they are doing they seem to be more conscious of their shortcomings and the problems they encounter in the day to day provision of services. In particular, we found it commendable that good programs were self-critical enough not to rest on their laurels but were constantly striving to be better.

In summary, what is exemplary about the programs listed here is a number of effective promising practices and a conscious struggling with the issue of how to assist people with severe disabilities to live full integrated lives in the community.

STATE AND REGIONAL SYSTEMS

Eastern Nebraska Community Office of Retardation (ENCOR)
Omaha, Nebraska

This is the regional agency which serves the 5 counties around Omaha, Nebraska. In 1983-84 ENCOR provided guidance, residential (including respite and in-home supports), vocational, educational, and support services for 1079 people. Within this service region institutionalization is unequivocally rejected as an option for anyone. Administrators at ENCOR feel the hallmarks of this region are a commitment to the developmental model, the provision of services in a person's "native" community, the use of generic resources, support for families, a public education initiative, and consumer participation.

Contact: Don Moray
Acting Director ENCOR
885 South 72nd Street
Omaha, Nebraska 68114
(402) 444-6500

Macomb-Oakland Regional Center
Mt. Clemens, Michigan
SITE VISIT

Macomb-Oakland is a state agency located in the two suburban counties north of Detroit. It serves approximately 1,120 people in community living arrangements (maximium size 6 people), an equal number in vocational services, and also has an extensive family support program. All residential and vocational services are operated by private nonprofit contract agencies. The centralized community services department has 5 divisions: 1) development for living arrangements, 2) case management, 3) professional support services, 4) placement, and 5) vocational services. In the area of residential services, Macomb-Oakland's adaptation of the foster home model is particularly noteworthy. Shortly, this region will have obtained the goal of having no person institutionalized because of mental retardation or developmental disabilities.

Contact: Gerald Provencal
Director
Macomb-Oakland Regional Center
16200 19 Mile Road
Mt. Clemens, Michigan 48044
(313) 286-8400

State of Michigan
Department of Mental Health
Lansing, Michigan

SITE VISIT

Michigan is a leader in deinstitutionalization. It has adopted a goal of returning all children to their local communities by 1986 and by December 1985 it will have closed 5 of its institutions. Three noteworthy initiative in this state are: 1) its innovative family subsidy program which provides direct cash subsidies to families of children with severe disabilities; 2) a developing regionalized service system which provides for local accountability, independent case management, innovative programming, and flexible funding; and 3) an extensive array of respite services which offer families real choices and control.

Contact: Ben Censoni
Community Services
Department of Mental Health
Lewis Cass Bldg.
Lansing, Michigan 48926
(517) 373-2900

In addition, one agency was also nominated as a model program.

Clinton-Eaton-Ingham Community Mental Health Board, Community Services For The Developmentally Disabled, Family Support Services. This agency provides respite services to over 100 families of children with severe disabilities. Within their respite allotment, families can purchase one or more types of respite from a "menu" of services, including foster home respite care, home-based respite care, family-friend respite care and drop-in day care.

Contact: Rite Charron, Director
Community Services for the Developmentally Disabled
838 Louisa St.
Lansing, Michigan 48910
(517) 394-5100

Project A R C
Albany, Georgia

This agency provides case management services for about 460 people living in an 8 county region. On the basis of individual need the agency contracts for necessary services. If appropriate services are not available, they will develop the supports which a particular family needs. The specific services which this agency is involved in include an integrated preschool; an early intervention in-home program; respite; monitoring and advocacy for people in small group homes; and recruitment, training, and support of foster families.

Contact: Annette Bowling
Director
Project A R C
601 Pine Ave.
Albany, Georgia 31701
(912) 888-6852

Region V Mental Retardation Services SITE VISIT
Lincoln, Nebraska

This is the regional service agency for the 16 county area around Lincoln, Nebraska. In 1983-84 Region V provided social services to 559 people, vocational services to 388 adults, residential services (including group living arrangements, apartments, and family placements) to 459 people, and respite for 79 children and adults. A strong committment to community integration and the rights of disabled people and their families pervades the people employed in this region. Services in this region are marked by 1) a move toward being non-facility based, 2) the use of generic resources, 3) small size, and 4) heterogeneous rather than homogeneous groupings.

Contact: Lynn Rucker
Executive Director
Region V Mental Retardation Services
2202 South 11th St. 4th Floor
Lincoln, Nebraska 68502
(502) 471-4400

Seven Counties Services
Louisvile, Kentucky

Seven Counties Services MR/DD Board, Inc. is a private, non-profit agency which is responsible for coordinating comprehensive community services in the region around Louisville. Direct services are primarily provided by affiliates who are under contract with the agency. The Seven Counties Board plans future services, monitors providers, operates a Direction (referral) service, and is developing work station employment opportunities. Throughout this region, there is a strong emphasis on community services for children including integrated preschools, family supports, and individualized residential placements. There are 5 themes which guide services in this region: 1) The importance of personal relationships; 2) services should be small and personal; 3) the individual, not the program, is central; 4) children, including those with behavior problems and serious medical needs are best served in a family setting; and 5) constant internal and external evaluation is crucial.

Contact: Jeff Strully
MR/DD Program Director
Seven Counties Services
620 South Third St.
Louisvile, Kentucky 40202
(502) 589-4861

In addition two agencies in the Seven counties region were individually nominated as model programs.

Community Living provides residential supports for 28 people in individual placements, 12 in small group homes, and 17 children placed with families.

Contact: Steven Tullman
Community Living
1347 South Third St.
Louisville, Kentucky 40208
(502) 637-6545

Community Connections serves 19 people through family placement and 20 individuals by in-home supports through their medicaid waiver services.

Contact: Pat Hall
Community Connections
1146 South Third St.
Louisville, Kentucky 40203
(502) 584-1239

RESIDENTIAL SERVICES

Boise Group Homes
Boise Idaho

This agency provides residential services to 34 people with severe disabilities. They were specifically nominated for their 4 homes which serve 4 or 5 people. They place a particular emphasis on preparing the direct service staff to consciously focus on how they can best aid the social integration of the people they serve.

Contact: Michael Day
Program Director
Boise Group Homes
1736 No. Five Mile Rd.
Boise, Idaho 83704
(208) 375-5155

Community Living
Yakima, Washington

This agency provide residential supports for 96 people of whom 15% have severe disabilities, particularly serious challenging behaviors. Eight individuals live on their own while the rest live in pairs. All decisions on these pairings are made by the tenants themselves. The staff is on-call 24 hours a day but does not live in any of the apartments with the tenants

Contact: Mary Margaret Cornish
Community Living
303 West Chestnut
Yakima, Washington 98902
(509) 575-3621

Community Resource Center
Bronx, New York

Most of the people living in the 5 homes administered by this agency have a variety of complex medical needs. A recent systematic analysis of their case histories revealed that these individual are in better physical condition and are receiving more services since they moved into the community. This agency has, in practice, worked through all of the hypothetical problems which are offered as a rationale for retaining people with serious medical need in institutions.

Contact: Sr. Barbara Eirich
Community Resource Center
235 East 149th St., Apt 2F
Bronx, New York 10451
(212) 292-1705

Community Services for Autistic Adults and Children
Residential Program
Rockville, Maryland

This program supports 55 people in 2 to 4 person residences. Staffing patterns for each of these homes is totally individualized based on the particular needs of the people living there.

Contact: Patricia Juhrs
Director
Community Services for Autistic Adults and Children
751 Twinbrook Parkway
Rockville, Maryland 20851
(301) 762-1650

East Mt. Airy Neighbors, Inc.
Philadelphia, Pennsylvania

This agency provides residential supports to 44 adults, 15 of whom have severe/profound mental retardation, challenging behaviors, and/or multiple disabilities. There are 4 group homes for 6 people, 4 apartments with 3 tenants each, and 4 apartments with 2 tenants. The agency is committed to becoming an intregral part of the Mt. Airy community.

Contact: James Hughes
Director
East Mt. Airy Neighbors, Inc.
820 East Vernon Rd.
Philadelphia, Pennsylvania 19119
(215) 849-3377

Gig Harbor Group Home
Gig Harbor, Washington

This service provides a home for 5 adults with severe /profound mental retardation. They use the Neighborhood Living model (cf. Appendix I). There is a strong emphasis on the development of relationships outside the home.

Contact: Kathy Easton
Gig Harbor Group Home
6823 Soundview Dr.
Gig Harbor, Washington 98335
(206) 851-3716

Katrina Project
Autism Service System
Huntington, West Virginia

The name of this project refers to the single person who this program is designed to serve. Katrina lives in her own apartment where she is supported by a number of staff people. Philosophically the agency believes that a person does not need to be prepared to live in the community--you just go right ahead and live in a community like everyone else.

Contact: Ruth Sullivan
Director
Autism Service System
101 Richmond St.
Huntington, West Virginia 25702
(304) 523-8269

Lynch Homes
Abington, Pennsylvania

This private-for-profit agency has a range of residential settings for 118 people many of whom are described as profoundly mentally retarded and medically fragile. They have a growing number of small homes (23 settings for 3 persons). These small homes were developed when other agencies refused to accept some of the residents as being "too handicapped" to live in small community settings.

Contact: Henry Lynch
Director
Lynch Homes
1355 Old York Rd.
Abington, Pennsylvania 19001
(717) 787-6057

Nebraska St. Group Home
Residential Care for the Developmentally Disabled, Inc.
Oshkosh, Wisconsin

This agency provides residential supports for 116 individuals. The Nebraska St. house is home for 6 people who are classified as autistic. Several of these individuals were considered to be too difficult to be served in anything but a "secure" setting, until they were accepted by this agency. It is worth noting that flexibility in funding and staffing have made it possible for the very complex needs of these people to be met in the community.

Contact: Richard Luecking
Director of Special Programs
Residential Care for the Developmentally Disabled, Inc.
1628 No. Main St.
Oshkosh, Wisconsin 54901
(414) 235-6560

Options in Community Living
Madison, Wisconsin

This agency provides supportive apartment living for 100 adults. People live alone or in groups of 2 or 3. Approximately 20 of these people live with paid roommates/attendants in order to see to their extensive needs. The money for these attendants goes directly to the residents who, with agency assistance, hire their own aides. A range of specialized supports are also provided by the agency staff.

Contact: Gail Jacob
Program Director
Options in Community Living
1954 East Washington Ave.
Madison, Wisconsin 53704
(608) 249-1585

Pacific North Community Services
Burlington, Washington

This small agency provides residential supports to 6 individuals in 2 apartments. This program sees itself as supporting people in their homes, "people don't move on as they develop--the program and the staff move on." There is a conscious systematic approach to integrating people into their community.

Contact: Sue Stoner
Program Director
Pacific North Community Service
P O Box 211
Burlington, Washington 98233
(206) 757-6810

TARGET
Westminister, Maryland

This agency operates 5 homes with 2 or 3 people living in each house. Their most recent homes were developed using a approach which first defined the needs of the residents then fashioned an environment to meet those needs. Most of the people served by this agency are labelled severely or profoundly retarded, multiple handicapped, or medically fragile and have spent most of their lives in a large state institution.

Contact: Donald Rabush
President
TARGET
1015 Oak Dr.
Westminister, Maryland 21157
(301) 848-9196

**Westport Associates
Westport Massachusetts**

This agency was established to provide permanent homes (3 locations) for 10 individuals with severe disabilities. The administration has made a conscious decision that this is all that they can do and still maintain high quality personalized homes. Therefore, they have refused opportunities to expand their services. Everyone in the agency is intimately involved in direct service. Staffing problems, even with a demanding work schedule, have been avoided because of good pay, individualized training, and a collegial relationship among all the staff. This agency exemplifies a major effort to transform the group home model into secure, longterm, individualized homes.

Contact: Ms. Sheila St. Auben
Executive Director
Westport Associates
PO Box N348
Westport, MA 02790
(617) 675-5710

Working Organization for Retarded Children (WORC) SITE VISIT
Flushing, New York

This agency serve 24 people in 4 settings. Many of the people served in these homes are some of the most severely disabled people effected by the Willowbrook decision. There is a strong emphasis on the role of the direct service staff, an awareness of the importance of relationships, an understanding of the integrated approach to therapies, and a committment to the principle of normalization which distinguishes these homes as models of integration in a large urban community.

Contact: Kathy Schwaninger, Executive Director
WORC
28-08 Bayside Lane
Flushing, New York 11358
(212) 787-4075

FAMILY SUPPORT SERVICES

Active People
Midland ARC
Midland, Michigan

This service is a social recreation program which enables people with developmental disabilities to use generic resources in the community. All programming is done individually on a 1 to 1 basis and is geared toward the unique interest of each participant.

Contact: Myrna Bartlett, Coordinator
Active People
Midland ARC
1714 Eastman Rd.
Midland, Michigan 48641-1491
(517) 631-4439

Extended Family Program
Children's Clinic and Pre-school
Seattle, Washington

This project was intended (funding has ended) to help families develop their "natural resources" for the support of their disabled members. This was done by aiding families to extend their support system by seeking to actively involve relatives, friends, and neighbors. In some cases volunteers were used to expand the network of families who were essentially isolated.

Contact: Judy Moore, Deputy Director
Children's Clinic and Pre-school
1850 Boyer East
Seattle, Washington 98112
(206) 325-8477

Family Support Program
Madison, Wisconsin

The purpose of this 11 county program is to provide families with whatever they need to prevent the institutionalization of their disabled member. The program provides a "menu" of 17 services plus an information and referral service for the families they serve. It also serves a training and education function for the counties in the region to help county staff people develop skills in supporting families.

Contact: Beverly Doherty, Director
Family Support Program
Developmental Disabilities Office
Division of Community Services
PO Box 7851
Madison, Wisconsin 53707
(608) 266-7469

Family Support Services Department
Calvert County ARC
Prince Frederick, Maryland

The intent of this program is to prevent any person 22 years of age or younger from being institutionalized. They provide respite, specialized family support, and integrated day care to approximately 50 people with developmental disabilities and their families. The specialized family support component attempts to help parents obtain any service or piece of special equipment which the family sees as needed in order to maintain a disabled member at home.

Contact: Kimberly Gschiedele
Director
Family Support Services Department
Calvert County ARC
Calvert Executive Plaza
P O Box 1860
Prince Frederick, Maryland 20648
(301) 535-2413

Family Support Services
Erie, Pennsylvania

This program provides a comprehensive array of family support servcies to Erie County, Pennsylvania. It is funded by the county Mental Health/Mental Retardation Department. The services available include family aide-sitter/companion, respite, recreation, in-home behavior management, parent counseling, sibling support, consultaion on sex education, health professional training, resource guides, and money management.

Contact: Ms. Kathy Kinol
Family support services
Dr. Gertrude Barber Center
136 East Ave.
Erie, Pennsylvania 16507
(814) 453-7661

VOCATIONAL SERVICES

Community Options, Inc.
Belchertown, Massachusetts

This agency provides direct training and follow along support to 28 people with a variety of disabilities who are employed in the community. Two approaches are used to finding employment opportunities for disabled people. The agency either finds an individual job in an existing community business or underwrites the start up cost of a small business (e.g., florist shop, copy center, etc.) which will employ handicapped and non-handicapped people.

Contact: Carol Shelton
Director
Community Options, Inc.
P O Box 962
Belchertown, Massachusetts 01007
(413) 323-6508

Community Services for Autistic Adults and Children
Vocational Program
Rockville, Maryland

This agency supports 40 adults working in groups of 1 to 3 in community businesses with a staff person. A careful effort is made to match each person with a job where his or her abilities will be maximized and any idiocyncratic behaviors will be minimize.

Contact: Patricia Juhrs
Director
Community Services for Autistic Adults
and Children
751 Twinbrook Parkway
Rockville, Maryland 20851
(301) 762-1650

Community Work Services
Madison, Wisconsin

This agency provides individually tailored training, assistance, and support for the 35 people they serve in Dane County. It services are based on the belief that people with severe disabilities are best served by working in individually arranged jobs alongside non-handicapped people. A variety of supports are available including assessment, job development/placement, job modification/adaptation, on-the-job-training, onsite support, follow up, and coordination of client's referral to other services which enhance their vocational functioning. Supports are provided as frequently and for as long as the individual may need them.

Contact: Betsy Shiraga
Community Work Service, Inc.
1245 E. Washington Ave.
Suite 276
Madison, Wisconsin 53703
(608) 255-8711

Kaposia Developmental Learning Center
St. Paul, Minnesota

This agency is in the process of changing from a typical day activity center to an integrated placement and support service. At present 31 people are employed at integrated jobs, while 44 remain in the sheltered setting. The plan is to completely eliminate the sheltered component and continue supporting people in their community jobs "forever."

Contact: Jacqueline Miynarczyk
Kaposia Developmental Learning Center
179 East Robie St.
St. Paul, Minnesota
(612) 222-9291

New England Business Associates (NEBA)
East Hampton, Massachusetts

This agency serves 40 individuals who have been evaluated as "unfit for work" whose only other option is a day treatment program. The agency locates jobs and arranges for long-term support for people with specialized needs. In addition, they also do staff training for more traditional vocational providers.

Contact: Kathy Moore
Director
New England Business Associates (NEBA)
27 Higgins Ave.
East Hampton, Massachusetts 01027
(413) 536-0221

Project Transition
Washington County Mental Health Center
Barre, Vermont

This project is part of a comprehensive service system based in a regional mental health center. It provides job development, training, and long-term support for 44 individuals who have "long-term training needs." Special emphasis is placed on matching the person to the job and developing the on-site supports which a person needs to survive without an agency employee always being present.

Contact: William Ashe
Director of Adult DD Services
Project Transition
Washington County Mental Health Center
Barre, Vermont 05641
(802) 479-2502

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